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‘Factors associated with psychological morbidity following pregnancy termination for fetal abnormality’.

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Psychological morbidity following pregnancy termination for fetal abnormality: moderating factors.

A systematic review of the literature

Keywords: *Prenatal Diagnosis, Fetal Abnormality, Psychological sequelae, Research Integration, Systematic Review, Psychological theories of grief.*

1. Abstract

Objective: The aim of this systematic review is to highlight the psychological effects of a termination of pregnancy for fetal abnormality (TOPFA). It will focus specifically on the moderating factors found to increase or reduce levels of distress.

Search strategy: Psychinfo, Medline, and Embase electronic databases were searched for terms relating to psychological impact, termination or pregnancy loss, and a diagnosis of fetal abnormality. Nine published reports, appearing between 2000 and July week 4 of 2012 met the inclusion criteria. *Selection Criteria:* Quantitative studies which used validated psychological measures to establish the psychological impact of TOPFA on women.

Data Synthesis: Psychological outcome and moderating factors were the topical focus. *Analysis:* A narrative framework was designed to synthesise the findings of primary studies by highlighting the most frequently used measures for determining the most prevalent psychological effects. Finally, any emerging moderating factors are presented and discussed.

Results: There is significant evidence that TOPFA produces long term psychological distress. Specifically, advanced gestational age and poor partner support resulted in worse outcomes in the areas of grief and post-traumatic stress. *Conclusions:* More prospective longitudinal studies are needed. Future studies must consider the impact of confounding factors such as premorbid psychological functioning or psychological traits. Furthermore, longitudinal studies need to be sensitive to changes in participant circumstances as a result of other recent traumatic life events which might have occurred after initial data collection (e.g. other traumatic experiences) and which so far undermine the reliability of published studies.

2. Background

Over the past decade, technological advancements in screening and diagnostic measures have resulted in improved early detection of fetal abnormalities (Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales, 2010). Detection of a severe congenital abnormality gives rise to a series of time nested and time-sensitive decisions (Sandalowski & Barasso, 2005), in which the majority of couples opt for termination (Salvesent, Oyen, Schmidt, Malt & Eik-Nes, 1997; Mansfield, Hopfer & Mareau , 1999). This has led to an increasing number of terminations of pregnancy for fetal abnormalities (TOPFAs), currently around 47 per 10,000 total births in the UK (26 per 10,000 before 20 weeks' gestation and 20 per 10,000 from 20 weeks' gestation) (The British Isles Network of Congenital Anomaly Registers, BINOCAR, 2011). Furthermore, these figures are likely to dramatically underestimate the prevalence of TOPFA as the registers do not cover the whole of the UK.

The highest rate of TOPFA was associated with chromosomal abnormalities (21 per 10,000 total births), followed by nervous system anomalies (15 per 10,000 total births) and congenital heart diseases (7 per 10,000 total births) (BINOCAR, 2011). The majority of chromosomal abnormalities are terminated before 20 weeks' gestation due to screening for Down syndrome, whereas notifications with nervous system abnormalities and congenital heart disease are terminated from 20 weeks' gestation as they are structural anomalies which will be primarily detected at the 18+0 to 20+6 weeks fetal anomaly scan (Statham, 2002).

The events following a positive diagnosis of fetal abnormality are unique experiences, characterised by, the diagnosis itself (many are fatal but most are not), the options and choices available (there may or may not be the option to terminate, and individuals may or may not chose this option), and the availability and relative success of potential treatments. Additionally, it is difficult to predict the extent and severity of abnormalities, making prognosis a complex task. Factors such as severity of the abnormality, gestation age, and degree of compatibility with extra-uterine life are important considerations in the decision making process (Drugan et al, 1990; Mansfield et al 1999; Statham et al 2000). Taking the decision to terminate has been described as an 'almost inhuman' thing to have to do (Korenromp et al, 1992) and marks the beginning of a complex and conflicting experience of which little is known about the immediate and long term psychological

effects of this type of loss, or the factors which appear to make psychological distress more or less likely (Statham, 2002; Korenromp et al, 2007).
Factors believed to influence the strength of a relationship between two other variables, such as the relationship between TOPFA and psychological functioning are called moderator variables. They affect the direction and/or strength of the relation between an independent or predictor variable and a dependent or criterion variable.

Psychological research specifically focussing on the domain of therapeutic abortion can aid our understanding of the particular psychological processes that occur in the immediate and long term aftermath of TOPFA. Statham (2000) writes how "Many studies have described the distress, but few have measured it in any formal way with a view to answering specific questions with a clinical relevance" (p 732). This study aims to synthesise the findings of studies concerned with psychological morbidity following a TOPFA whilst focussing specifically on the presence of moderating factors thought to make distress more or less likely. Psychological morbidity is likely to include (although not be confined to) depression, anxiety, posttraumatic symptoms and grief (Adler et al, 1992).

2.1 Objectives

The aims of this study are to answer the following questions;

1. What are the psychological effects of TOPFA?
2. What moderating factors appear to increase or reduce levels of distress following TOPFA?

Specifically, these questions will provide vital information pertaining to a woman's psychological outcome following TOPFA and will help guide clinicians who offer guidance, support and aftercare at this difficult time.

3. Methods

Systematic Literature Search

3.1 Inclusion Criteria/ Exclusion Criteria*;* In order to answer the aforementioned questions, a number of a priori inclusion and exclusion criteria were developed and defined.

Literature was included in the review if it;

a) Included women who had experienced a termination of pregnancy for fetal anomaly.

- A pregnancy termination is defined as the elected termination of a pregnancy before 24 weeks because of the detection of fetal abnormalities.

b) Explored the psychological impact of losing a baby due to fetal abnormality, including a measure of psychological impact using at least one validated tool (quality threshold).
c) Identified moderating factors associated with increased or reduced psychological distress.
d) Reported data relating to the time since the TOPFA.
e) Quantitative studies meeting the aforementioned criteria.
f) Published since 2000 (due to vast policy changes in screening programmes due to technological developments occurring in the last decade)
g) Had been subject to peer review.
h) Written in English (for practical purposes)

3.2 Sources of data

Host multi-database Ovid was selected as the primary electronic data source enabling the removal of duplicates between sister search engines. Specifically, a systematic search was performed within OVID of the following electronic bibliographic databases;

PsychINFO, 2000 - July week 4, 2012
Medline, 2000 - July week 4, 2012
Embase, 2000 -2012, Week 30

Collectively, these databases include research efforts and literature from the disciplines of Social Sciences, Nursing and Medicine, therefore allowing rigorous examination of risk factors associated with TOPFA from multiple sources, reflecting the interdisciplinary context of this phenomenon. Alerts were then activated in order to draw the researcher's attention to new relevant studies.

Key terms were inputted into each database individually and through the process of 'term mapping'; terms providing the best return from each database were combined to provide a comprehensive scope of the target concept. The group of terms identified were then

combined and applied across all databases. Terms related to three key parameters included; a) terms related to psychological impact b) terms related to bereavement and pregnancy loss c) terms related to a diagnosis of fetal abnormality. Subject headings, where available, were exploded to further facilitate the capturing of studies with variations in terminology that were still relevant to the key concept. Terms directly related to risk factors were not included in the search because they restricted the search providing too few returns.

Editorials, commentaries, conference reports and strategy papers were searched for references, but were not included in the systematic review. Citation-tracking of all primary study articles provided an additional search strategy.

3.3 Search Process

Initially, the titles of all citations were examined to determine their relevancy. Where the author could not conclude suitability, the abstracts were examined against the inclusion criteria. If the information provided in the abstract was also deemed insufficient to determine suitability, the full text versions were obtained. The majority of citations were excluded at the stage because they failed to include or report a validated measure of psychological impact or were descriptive accounts.

3.4 Search terms:

Please see Appendix I for details of the search terms and associated results.

3.5 Data Extraction:

Studies were heterogeneously varied with respect to their design (case-controlled, cohort or cross sectional), the timing of outcome (targeting immediate and longer term reactions) and the psychological measures used to measure outcome. It is well documented that meta-analyses in the presence of serious publication and/or reporting biases (similar to those found in the included studies) are likely to produce an inappropriate summary. As such, Meta-Analysis was not deemed appropriate for the purpose of contrasting and combining the results (especially as non-significant results were often omitted/ not reported). Instead, a narrative framework designed to describe the similarities of findings and outcomes, in terms of the psychological impact and factors' affecting this is provided.

4. Results

After removal of duplicates, a total of 355 abstracts were obtained using the aforementioned search strategy. This included studies limited to English language, peer review and published post 2000 (to best reflect the current context of TOPFA). Excluded from analysis were reviews, commentaries, comments letters and editorial review articles. However, citation tracking identified one further study that was not accounted for in the original search strategy. Of the 355 studies, only 9 studies fully met the inclusion criteria. 339 studies were excluded for obvious violation of the inclusion criteria (i.e. unrelated subject matter), leaving 17 potential studies. Of these, 3 had no measure of psychological outcome, 3 records were review papers, and 2 records were categorised as editorial reviews or comments letters.

These results are presented on the following page in Figure I.

A summary of the main findings including details of the psychological outcomes and the factors which appear to increase or reduce psychological distress are reported in Table 1.

4.1 Study Selection

Figure I. PRISMA diagram representing the flow of studies through the review

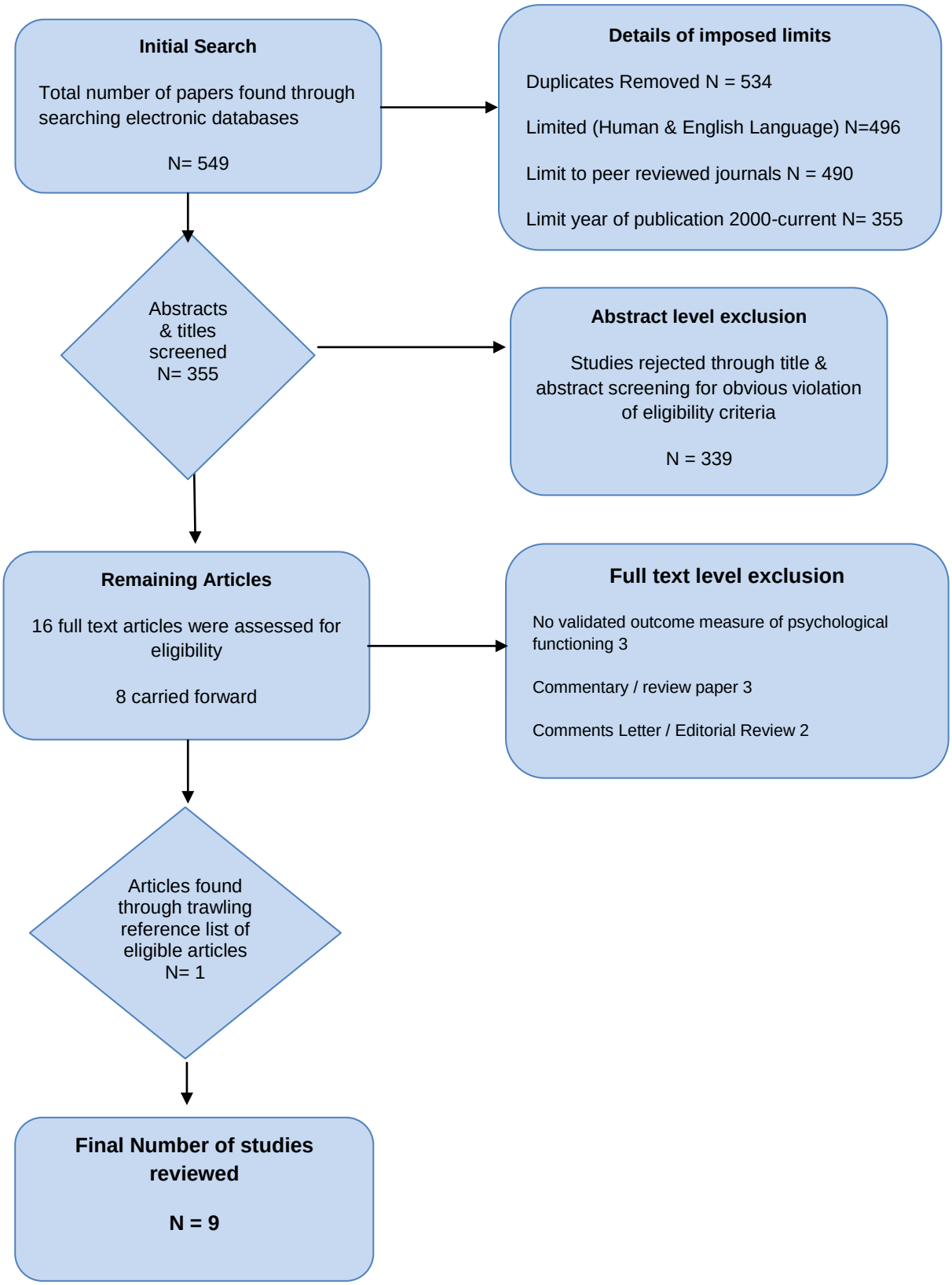

Table 1 Research overview of psychological outcomes following TOPFA with emphasis on moderating factors

KEY: *P<0.05; **P<0.01; ***P<0.001; ****P<0.0001; #P<0.10 (trend); n.s. = not significant

Study Number	Author (s) Country	Publication year	Aims	Sample	Stated Methodology	Psychological outcomes & Time at which psychological measures were taken post TOPFA/ Event	Analysis	Key findings
1	Davies, Gledhill, McFadyen, Whitlow & Economides UK	2005	To ascertain and compare psychological morbidity in women undergoing first- vs. second-trimester TOPFA.	N= 30 (14) First trimester TOPFA (16) Second trimester TOPFA	Cohort Study	General Health Questionnaire – 28 (GHQ-28) Becks Depression Inventory (BDI) Perinatal Grief Scale (PGS) Impact Events Scale (IES) 6 week 6 months 12 months	Crude odds ratios (OR) with 95% confidence intervals were reported for effect of gestational age at TOP on measures of psychological morbidity. A P-Value of 0.05 indicated statistical significance.	High levels of distress in both groups at each time point, as indicated by scores on the GHQ, PGS, BDI and IES. • Combining results for both groups, 67% screened positive (scored above the pre-determined cut-point for psychiatric disorder) for post-traumatic stress at 6 weeks, 50% at 6 months and 41% at 12 months. • For emotional distress (GHQ) the rates were 53% at 6 weeks, 46% at 6 months and 43% at 12 months. • For grief (PGS) the rates were 47% at 6 weeks, 31% at 6 months and 27% at 12 months. • For depression (BDI) the rates were 30% at 6 weeks, 39% at 6 months and 32% at 12 months. TOPFA in second trimester indicating advanced gestational age had higher levels of post-traumatic stress and depression than their first trimester counterparts when en assessed 6 weeks after the procedure (OR, 9.3;95% CI, 1.5–57.7). This differential did not persist at a statistically significant level at the 6- or the 12-month follow-up.
2	Kersting, Dorsch, Kreulich, Reutemann, Ohrmann, Baez & Arolt Germany	2005	To compare the extent of traumatic experience and grief among women several years after TOPFA with that of women shortly after TOPFA and with women after	N = 208 (60) women 14 days after TOPFA (83) women 2-7 years after TOPFA (60) full term delivery of a healthy baby (control)	Case control pilot Study	Impact Events Scale (IES) Perinatal Grief Scale (PGS) 14 days 2-7 years	To compare results of study sample and comparison sample, means and standard deviations were calculated. To check for difference in the stress responses between the	IES-R mean total scores were; 18.62 (SD = 6.9)14 days post event > 16.13 (SD= 9.4) 2-7 years post event > 4.60 (SD= 4.67) spontaneous delivery of a full-term healthy child. A one-way ANOVA revealed statistically significant differences between the three samples. Significant results were recorded in the cumulative value of the IES-R (F= 74.146, P= 0.000) and in the subscales; Intrusion (F=60.03 p= 0.000), Avoidance (F= 49.29 p=0.000) and Hyperarousal (F=49.29 p=0.000)

			spontaneous delivery of a full-term healthy baby.				study sample and comparison sample a one-way ANOVA with Scheffe comparisons was used. An unpaired t-test was used to evaluate differences in grief between the study sample of women 2-7 years after TOP and the comparison group 14 days after TOP.	Women after TOP (both 4 years and 14 days after TOP) reported a significantly higher degree of trauma than the control. With respect to the experience of grief, mean PGS scores were; 2.86 (SD= 0.55) 14 days post event > 2.67 (SD=0.62) 2-7 years post event. Only for the subscale Fear of Loss were significant differences registered between the groups.
3	Kersting, Kroker, Steinhard, Steinhard, Hoernig-Franz, Wesselmann, Luedorff, Ohrmann, Arolt & Suslow Germany	2009	This prospective longitudinal study aimed to compare the course of posttraumatic stress responses, depression and anxiety in women after TOPFA and women after Very Low Birth Weight (VLBW) delivery.	N=170 (62) TOPFA (43) VLBW (65) Control group: women who delivered healthy infants	Prospective longitudinal study.	Structured Clinical Interview for DSM-IV patient edition (SCID-IV-P) The Mongomery-Asberg Depression Rating Scale (MADRS) Impact of Events Scale (IES) Becks Depression Inventory (BDI) State-Trait Anxiety Inventory (STAI)	Chi2-tests were used to analyse differences on nominal data between three study groups Cochrances Q were used to analyse differences within groups Single time point data was analysed using univariate ANOVAs Tukey's HSD test (variance-homogeneity) & Tamhane Test (inhomogeneous variables) was used to analyse group factors.	**Psychiatric diagnosis** Percentage of psychiatric life time diagnoses as assessed by SCID interview did not differ between groups (Chi^2 = 1.25, *df* = *2*, p=.535, n.s), however significant difference 14 days post partum (Chi^2= 7.10, df=2, p<.029; 18.6% of the women after preterm birth fulfilled diagnostic criteria according to DSM-IV, marginally significant more women after TOPFA (22.6%, SR= 2.0) and significantly less women in the control group (6.25, SR=2.6) were diagnosed with a psychiatric disorder. **(as a function of time)** Groups differed significantly at all time points in time (Chi^2 from 6.80 to 15.95, *df* =2, *p* between 0.001 and 0.003.Especially, across time no significant reduction in percentage of psychiatric diagnoses was found, neither in women after TOPFA (q=1.06, *df*=2, *p*=5.89, n.s.), nor in women after preterm birth (Q=1.14,*df*=2,**p**=.569, n.s.) **Psychopathology** ANOVAs revealed significant group differences in all psychopathological symptoms two weeks after the event. According to Cohen's (1988) estimated effect sizes on posttraumatic stress (IES-R, intrusion, avoidance and Hyperarousal: Partial n^2 = 0.207 and 0.227), and anxiety (STAI-state, STAI-trait: partial n^2 = 0.259 and 0.201, HAMA-total score, HAMA-ps: n^2<0.2) were medium to small.

						14 days 6 months 14 months	Repeated measures ANOVA; i) between groups factor = TOP vs. VLBW vs. CON) ii) within subject factors = time (T1 vs. T2 vs.T3) Greenhhouse-Geisser applied for violation of sphericity. Post hoc tests included Tukey's HSD or Bonferroni's correction where appropriate.	Highest posttraumatic stress was found in women after TOPFA (Tahmene on all IES-scales: all *ps* <0.001) More intense emotional reactions in TOPFA with women in control group showing significantly less stress. **(as a function of time)** Significant interactions between group and time were revealed on IESR total (F=3.87, df=(3.62, 114), p=.0006), IES-intrusion (F=5.27, df=(3.65, 114), p=.0001), and IES-hyperarousal (F=2.76, df=(3.71, 114), p=.033). Estimated effect sizes according to Cohen (1988) were rather small (partial η2 ranging between 0.046 and 0.085), however significant. Following post-hoc analyses, posttraumatic stress decreased significantly in women after TOP [especially on IES-R and intrusion: from T1 to T2 and from T1 to T3; Bonferroni: all *ps*<0.01] and in the control group [from T1 to T2 and from T1 to T3 on IES-R, Bonferroni: all *ps*<0.041], whereas women after preterm birth did not change significantly on any scale measuring posttraumatic stress [(Bonferroni: all *ps* n.s.)]. Only on the subscale avoidance no significant interaction was found (F=1.10, df=(3.71114), p>.10, n.s.). Women after TOPFA showed significantly higher posttraumatic stress at all measuring points than women in the other groups (Bonferroni all ps<0.041).
4	Korenromp, Christiaens, van den Bout, Mulder, Hunfeld, Bilardo, Offermans & Visser. The Netherlands	2005a	To evaluate women's long-term psychological reactions after TOPFA in a large study sample. The principle aim was to identify moderating factors for psychological morbidity.	N= 254 women undergoing TOPFA < 24 weeks gestation	Cross sectional study	Inventory of Traumatic Grief (ITG) Impact of Events Scale-Revised (IES-r) Symptom Checklist-90(SCL-90) depression, anxiety & somatic complaints subscales.	Groups compared for equivalence in baseline characteristics using; Chi-square test or Fisher exact test (categorical measures) Student's t-test (continuous variables) Associations between subject characteristics and outcome	The scores on grief, posttraumatic stress (and its components), and psychosomatic symptoms were strongly inter-correlated (range of R's between 0.47 and 0.71). The means, SDs, and ranges of scores for grief were 45 (16; 29-119), total posttraumatic stress 20 (19; 0-82), depression 27 (12; 16-73), anxiety 15 (7; 10-48), and somatic complaints 18 (7; 12-48) respectively. Highest scores in low-educated women, in women with an advanced gestational age, and in women whose babies had an anomaly compatible with life. **Significant correlations between moderating factors and outcome measures** • Grief was independently predicted by three factors: education

						2-7 years	measures using; Spearman and Pearson correlation coefficients where appropriate Multiple linear and logistic regression analyses were conducted to identify independent factors.	(β = -3.99*), gestational age (β =0.74*), and lethality (β = -5.74*) • Posttraumatic stress was significantly predicted by the level of education (highest scores in low-educated women), while gestational age showed a trend toward significance (total and intrusion, p-values were 0.076 and 0.055 respectively. • Low educated women more often reported somatic complaints (β = -1.39)*; symptoms of both anxiety(β = 0.69#) and depression (β = 1.71**)- appeared to increase over time. • Perceived partner support had an independent effect on grief (β = -5.91***), posttraumatic stress (β = -4.47*), anxiety (β = -1.41#, p=0.071), and depression (β = -4.22**).
5	Korenromp, Christiaens, van den Bout, Mulder, Hunfeld, Bilardo, Offermans & Visser. The Netherlands	2005b	To examine the psychological responses to TOPFA in both men and women in order to find risk factors for poor psychological outcome.	N = 151 Couples	Cross-Sectional retrospective (Questionnaires)	Inventory of Traumatic Grief (ITG) Impact of Events Scale-Revised (IES-r) Symptom Checklist- 90 (SCL-90) depression, anxiety & somatic complaints subscales. 2-7 years	Groups compared for equivalence in baseline characteristics using; Chi-square test or Fisher exact test (categorical measures) Student's t-test (continuous variables) Associations between subject characteristics and outcome measures using; Spearman and Pearson correlation coefficients where appropriate	Majority of couples adapt well without evidence of psychopathology. Women had significantly higher levels of symptomatology on all of the outcome measures, both as a group and as an individually within the couple. The means and standard deviations of women as compared with men's scores for grief were 44.1 (16. 2) vs. 38.6 (11.4), total posttraumatic stress 18.1 (18.0) vs. 12.8 (16.6), depression 26 (11) vs. 20.8 (7.5), anxiety 14 (6.0) vs. 12.1 (4.5), and somatic complaints 16.9 (6.0) vs. 12.1 (4.5) respectively. Level of male-female difference ranged between p <0.0001(depression) and p<0.05 (anxiety). Level of intracouple difference ranged between p <0.0001 (Grief) and p<0.005 (anxiety). Some couples continued to encounter poor outcomes including depression and post-traumatic stress years later. The level of education was most consistently related to problematic outcome in both sex groups. For women the level of education and IES-r was (p= -0.28, N=151, p <0.001) and for somatic complaints was (p= - 0.16, N=151, p<0.05). Low-educated participants had more unfavourable scores on the psychological inventories in both genders.

6	Korenromp, Christiaens, van den Bout, Mulder, Hunfeld, Potters, Erwich, van Binsbergen, Brons, Beekhuis, Omtzigt & Visser The Netherlands	2007	This large prospective study investigated the consequences of TOPFA 4 months after the event. They aimed to assess psychological morbidity and identify factors influencing psychological outcome, such as personality characteristics, gestational age at termination and education.	N= 386 (217) women (169) men	Prospective Cohort study (Questionnaires)	Inventory of complicated grief (ICG) Edinburgh Postnatal Depression Scale (EPDS) Impact of Events Scale (IES) Symptom Checklist-90 (SCL-90) The Generalised Self Efficacy Scale (SES) <u>4 months</u>	Groups compared for equivalence in baseline characteristics using; Chi-square test or Fisher exact test (categorical measures) or Student's t-test (continuous variables) Associations between subject characteristics and outcome measures using; Spearman and Pearson correlation coefficients where appropriate. Stepwise multiple linear regression was used to identify independent factors	The four outcome measures were fairly inter-correlated on each occasion. The R-values ranged from 0.63-0.75 in women. The means and standard deviations of women as compared with men's scores for grief were 59.0 (20.4) vs. 47.8 (16.6), total posttraumatic stress 25.1 (15.2) vs. 16.9 (12.6), General Psychological Malfunctioning (SCL-90) 145.6 (53.1) vs. 121.5 (36.6), and post partum depression (EPDS) 8.4 (5.6) vs. 5.5 (5.2) All p levels representing male-female difference were p <0.0001 irrespective of outcome. Women had high levels of PTS and depression (44% and 28% respectively) The following predictors of adverse psychological outcome were found (β values listed for Grief (ICG), Post-traumatic stress (IES), General Psychological malfunctioning (SCL-90) and Post Partum Depression respectively (EPDS)) • High level of doubt in the decision period (β 3.60***, β 1.36 n.s, β7.49**, β 0.83**) • Partner support (β -10.11***, β -5.81*, β -37.07****,-3.81****) • Self-efficacy (β-0.81**, β-0.36 n.s., β-2.54****, β-0.29****) • Lower parental age (β -0.63*, β -0.41#, β -1.41#, β -0.08 n.s,) • Being religious (β 5.81*, β 4.68*, β 9.09 n.s., , β 1.15 n.s) • advanced gestational age (β 1.22***, β 0.64*, β -0.07 n.s., β -0.16 n.s.) Type of abnormality didn't impact on outcome.
7	Korenromp, Godelieve, Page-Chistiaens, van den Bout, Mulder, Gerard & Viser	2009	To investigate predictors of persistent problematic outcome that can be identified before and during the first 16 months after TOPFA.	N = 147	Longitudinal Prospective Cohort study	Inventory of complicated grief (ICG) Edinburgh Postnatal Depression Scale (EPDS) Impact of Events Scale	Groups compared for equivalence in baseline characteristics using; Chi-square test or Fisher exact test (categorical measures) Student's t-test	The psychological outcome measures grief, PTS symptoms, psychological malfunctioning, and depression were fairly inter-correlated on each occasion. The r values ranged from 0.59-0.74 at T1, from 0.65-0.79 at T2, and from 0.37-0.74 at T3 (*P*=.001 for all relationships). Four months after termination 46% of women showed pathological levels of posttraumatic stress symptoms, decreasing to 20.5% after 16 months. As to depression, these figures were 28% and 13%, respectively.

	The Netherlands					(IES) Symptom Checklist-90 (SCL-90) <u>4 months</u> <u>8 months</u> <u>16 months</u>	(continuous variables) Multilevel Analysis (mixed model option) was used to identify factors that had an independent effect on the time course of outcome measures. Fixed effects were considered for all random effects for elapsed time and participants.	• The percent of women who indicated severe, moderate and no feelings of doubt was 17, 45.6 and 37.4 respectively. • 12% had perceived pressure during the period of decision making • Partner support was generally perceived as excellent or sufficient, and < 5% of women reported no support at all. • The scores on the GSE inventory were similar on all occasions and showed extreme intra-individual stability over time (*P*=.99) Maternal age, level of education, having living children before TOP, the TOP method, estimated viability of the unborn, Down syndrome, and perceived pressure at decision making had no significant contribution to the models. Outcome at 4 months was the most important predictor of persistent impaired psychological outcome. • Being religious was associated with worse scores on grief and PTS symptoms (5.9 (2.59); *P* = .024 5.4 (1.9; *P* = .006) respectively. • An advanced gestational age at TOPFA was also associated with worse scores on grief and PTS symptoms (0.65 (0.37)[#] 0.63 (0.27); P = .020) • The presence of a new pregnancy at T2 or T3 was associated with better scores on SCL only (-13.3 (5.3); *P* = .014) • Women who experienced adequate or good partner support showed better scores on all outcome measures (ICG, -3.9 (1.6); *P* = .018, IES, -5.0 (1.6); *P* = .002, SCL, -11.6 (4.1); *P* =.005, EPDS, -2.0 (0.6); *P* = .0001) • Women who had experienced serious doubt about their decision had worse scores on grief (ICG) and psychological malfunctioning (SCL). • Self-efficacy was an important determinant of psychological functioning after TOPFA in each model, with poor self-efficacy related to more negative scores on the outcome measures (ICG, -0.55 (0.18); *P* = .002, IES, -0.35 (0.16); *P* = .025, SCL, -2.1 (0.4); *P* = .000, EPDS -0.29 (0.05); *P* = .0001. There were no significant interaction effects of elapsed time by any of the predictors regarding the 4 outcome measures. For all outcome measures, the distress rates declined over time, with the largest reductions

								to occur from T1-T2
8	Keefe-Cooperman USA	2005	To compare maternal loss in women who undergo TOPFA and women who experienced a miscarriage to determine if a difference in susceptibility to grief reactions exist and to identify the factors that differentiate the two groups and their needs.	N=85 (63) TOPFA (23) Miscarried	Cohort Study	Perinatal Grief Scale-Shortened (PGS-s) Perinatal Bereavement Scale (PBS) <u>12-24 Months</u>	An Independent-Samples *T*-Test procedure analyzed fixed nominal and ordinal variables related to PGS-S or PBS scores. A GLM Univariate procedure provided a regression analysis and analysis of variance for one dependent variable by one or more factors and or variables. The results allowed for several factors to be analyzed together in relation to PBS or PGS-S scores to explore the interaction of several independent variables.	The first hypothesis of this study was that females who terminate a wanted pregnancy would experience a greater vulnerability for grief complications. An Independent-Samples T-Test compared mean scores of the quantitative measures for both groups and found no significant differences between the miscarriage group and termination group as related to the PGS-S or PBS total scores. Five key fixed variables were found to be related to vulnerability of grief reactions related to PBS and PGS-S scores respectively: • A significant relationship was found between time since the most recent loss and the PBS total score (.044), time since the most recent loss and the PGS-S total score (.040), and time since the most recent loss and the active grief subscale of the PGS-S (.001). • Counselling was significantly related to both the PBS total scores (.003) and the active grieving subscale of the PGS-S (.022) reported by 65.9% of the respondents. • An important relationship was found between employment outside the home and the PBS-guilt subscale (.030), and employment outside the home and the PBS total score (.012) Women who worked outside the home achieved scores on the PBS total scale (mean score = 73.37) representative of less sadness, , anger, and preoccupation with the loss than women who were not employed outside of the home (mean score = 65.58). • Feeling responsible for the loss was related to both the PGS-S and the PBS total scores (.009 for each), the difficulty with coping subscale (.034), and the PBS-guilt subscale (.047). • A significant relationship was found between the greatest gestational age of all the perinatal losses and the PBS total (.018). Significantly, time was the only variable found to interact with other fixed independent variables in relation to the dependent PBS and PGS-S scores.
9	Burgoine, Van Kirk, Romm, Edelman, Jacobson & Jenson	2005	This study was undertaken to compare grief resolution after Dilation & Evacuation (D&E) or Induction or	N= 49 women 22 -D&E 27-IOL	Prospective cohort study	Edinburgh Postnatal Depression Scale (EPDS) Perinatal Grief Scale (PGS)	Data were analyzed with; X2 tests(categorical variables) Mann-Whitney U tests	There was no significant difference in depression incidence (EPDS); on enrolment 61.9% (D&E) vs. 53.8 %(IOL), (P = .579, n.s.), at 4 months 23.5% (D&E) vs. 14.3 %(IOL), (P = .252, n.s.)

	USA		labour (IOL) for second trimester			4 months 12 months	Independent and paired sample t tests.	at 12 months; 27.3% (D&E) vs., 20.0 %(IOL), (P = .696 n.s.) Or on the PGS at; 4 months (74.1 vs. 90.2, P = .351) 12 months (73.3 vs. 86.4, P = .658).

4.2 Study Characteristics

The study characteristics of the nine studies in the review are presented in Table 1. They include prospective and retrospective designs including a mixture of case-controlled, cohort and cross sectional studies.

4.3 Study Location

Study location is detailed in Table 1. All studies with the exception of one UK based study were conducted overseas.

4.4 Assessment of Psychological Morbidity

All nine studies included outcome data for psychological morbidity using a validated measure. Grief, PTS, somatic complaints, depression and anxiety were investigated after TOPFA with seven of the studies included a comprehensive assessment measuring each of these areas.

4.4.1 Grief

Grief was measured in all but one study (Kersting et al, 2009) and included a variety of measures including the Perinatal Grief Scale (PGS; Potvin, Lasker, & Toedter, 1989), the Inventory of Complicated Grief (ICG; Prigerson & Jacobs (2001), and the Inventory of Traumatic Grief (ITG; Prigerson & Jacobs, 2001; Boelen, 2003); which varied considerably in terms of the observed prevalence and longevity of grief reactions. The most common measure the PGS, was employed by four studies [1, 2, 8, 9] to report significant short term grief reactions measured between 14 days and 12 months after the event. Two of the studies found evidence of grief lasting up to 24 months after the termination, and one further study explored enduring grief reactions persisting as long as 7 years post event. Additionally, two studies used the ICG [6, 7] at 4 months post TOPFA and found that almost 10% of women had pathological scores. However, only 2% of these remained at a pathological level by 16 months follow up (despite the overall mean ICG scores remaining unchanged). Finally, Korenromp et al (2005; 2005) used reductions in ITG scores [4, 5] as evidence to conclude that women generally adapted well to grief and had improved psychological outcomes at long term follow-up.

High attrition (31- 51%) and the potential loss of those initially appearing to be worse affected by grief may significantly undermine the prevalence of those with long term pathological grief. Nevertheless, most respondents appear to adapt well to their loss, demonstrating reduced scores on repeated measures.

4.4.2 Post-traumatic Stress (PTS)

PTS was measured in all but two [8, 9] studies using the Impact of Events Scale (Horowitz, Wilner & Alvares, 1979). This scale is used to assess subjective distress and post-traumatic stress reactions after major life events such as TOPFA. It includes three subscales including; intrusive experiences, avoidance of thoughts and symptoms of hyperarousal (Weiss & Mamar, 1997). A number of studies reported a high proportion of pathological scores for PTS, in which initial high levels of distress were highly predictive of persistent suffering. Surprisingly, unlike grief, PTS appears more enduring in nature and results reflect a general trend in persistent symptomology. Furthermore, Korenromp (2007) concluded that PTS was the only outcome measure which did not correlate with scores on the Generalized Self Efficacy Scale (GSE, Wegner, Schwarzer & Jeruzalem, 1993) indicating that PTS symptomology may not be affected by an individual's self-confidence in coping with emotional demands.

4.4.3 Depression & Anxiety

Seven studies included some measures of either depression or depression and anxiety combined [1, 3, 4, 5, 6, 7, 9]. Measures included the General Health Questionnaire – 28 (GHQ-28, Goldberg & Hillier, 1979), Becks Depression Inventory (BDI, Beck et al. 1961;1988), The Mongomery-Asberg Depression Rating Scale (MADRS, Mongomery & Asberg, 1979), Symptom Checklist- 90 (SCL-90, Arrindel, W.A. & Ettema, J. (1986) depression, anxiety & somatic complaints subscales and the Edinburgh Postnatal Depression Scale (EPDS, Pop Komproe & Son, 1992; Cox, Holden Sagovsky, 1987). Case controlled studies illustrated significant interactions of group and time on measures of depression. This suggests a differential course of depressive symptoms across time for women following TOPFA. Furthermore, numerous studies reported a gradual reduction in depressive symptoms in the first year after termination, with a slight increase around the 12 months point. Findings from a number of studies indicate that of all the potential psychological outcomes, depression is the most likely to have late onset.

4.5 Factors possibly influencing psychological outcomes

A summary of those factors identified as being most consistently associated with scores on psychological outcome measures will follow.

Advanced gestational age at TOPFA was mainly associated with worse psychological outcomes in the areas of grief and PTS [1, 4, 6, 7, 8]. Earlier gestational age was independently associated with retrospective doubt about decision to terminate (Korenromp et al 2005b). None of the studies found gestational age to correlate with anxiety, depression, or somatic complaints. The effect sizes across studies were all small to medium.

Good social and partner support [4, 5, 6, 7] appeared to be a significant protective factor and was consistently associated with better widespread psychological outcomes, including grief, PTS (particularly avoidance and arousal), depression and to a lesser extent anxiety. The effect sizes associated with partner support were all medium to high indicating a stronger relationship.

In a small number of studies, level of education (2) was consistently related to problematic outcome with low educated participants having more unfavourable scores on psychological inventories. The effect sizes were small to medium for grief and somatic complaints but were significantly higher for PTS symptoms.

The method of termination [6, 7, 9] did not appear related to psychological outcome. Korenromp et al (2007; 2009) concluded that the termination procedure did not relate to scores on measures of grief, PTS or psychosomatic complaints, however appeared related to levels of doubt regarding the decision to terminate. Corroborating this finding, Burgoine et al (2005) assessed method of termination as a primary aim and found no significant difference between women who chose Dilation and Evacuation (D&E) or Induction of Labour (IOL) which seems more significant to the outcomes of men.

Level of self-efficacy was measured using the Generalized Self Efficacy Scale (GSE, Wegner et al., 1993). Greater self-efficacy was associated with better outcomes and appeared to reduce the impact of grief, poor psychological functioning and symptoms of depression [6, 7]. PTS symptoms were not correlated with self-efficacy (Korenromp et al., 2007; 2009). Scores on the GSE were stable across time and represent one of the first attempts to include a measurement of stable personality traits into the design.

Maternal age [4] did not seem to impact upon psychological outcome and was only weakly associated with PTS as measured by the IES (1979) (Korenromp et al, 2005a). When entered into a regression model it was not determined as a significant predictor of psychological morbidity.

Finally, level of doubt over the decision to terminate [6, 7] appeared to relate to high levels of grief, general psychological functioning and post-partum depression but not PTS (Korenromp et al., 2007; 2009).

4.6 Assessment of Methodological Quality

Critical appraisal is defined as 'the process of carefully and systematically examining research to judge its trustworthiness, and its value and relevance in a particular context' (Burls, 2009; p2). Good quality high relevance research is pivotal to scientific research and explicit systems such as peer review, reporting guidelines and appraisal tools help facilitate the quality appraisal process (Gough, Oliver & Thomas, 2012). With this in mind, only studies subject to peer review were included in this systematic review.

Critical appraisal tools provide a structured approach for assessing quality and relevance enabling the reviewers to record and make explicit their judgments. However, few tools document evidence of validity of their items or reliability of use and often fail to reduce bias (Kattrak et al, 2004; Higgins & Green, 2011).

As there is no 'gold standard' for assessing methodological quality, a quality assessment tool was developed specifically for this review (Appendix 2) with reference to similar generic tools (e.g., Critical Appraisal Skills Programme (CASP), 2004; Critical appraisal notes and checklists, Scottish Intercollegiate Guidelines Network (SIGN; 1995) adaptations were made including items specific to the assessment of psychological outcome and identification of risk factors following TOPFA. The quality assessment tool contained 13 questions that examined five potential sources of bias, including: design, participants, features of psychological assessment (depression, anxiety, grief, and post-traumatic stress), statistical analysis and obstetric data. For each question, a rating out of three was awarded and an overall score was an aggregate of points from all items. Finally, whilst this review has focussed on the traditional epistemic dimension of methodological and theoretical robustness, other conceptualisations of quality in research exist, focussing more on qualities relating to capacity-building, value for people, and economic effectiveness (Furlong & Oancea, 2006).

The methodological quality was found to vary across the studies, and is summarised in Table 2.

Table 2: Results of Quality Appraisal

Study		Design		Participants						Assessments		Statistics			Obstetric data	Overall
		1.	**2.**	**3.**	**4.**	**5.**	**6.**	**7.**	**8.**	**9.**	**10.**	**11.**	**12.**	**13.**	**14**	
1	Davies et al 2005	*	*	**	*	*	*	**	**	***	**	*	**	*	**	21
2	Kersting et al 2005	*	***	**	**	*	*	*	*	***	*	*	**	*	**	22
3	Kersting et al 2009	*	***	**	*	***	***	**	*	**	***	***	***	***	**	31
4	Korenromp et al 2005a (n=254)	*	n/a	***	*	*	***	**	***	***	***	*	**	***	**	28
5	Korenromp et al 2005b	*	n/a	***	**	**	**	**	**	***	***	*	**	***	***	29
6	Korenromp et al 2007	*	*	***	**	***	***	*	***	***	***	*	*	***	***	34
7	Korenromp et al 2009	*	*	***	**	*	***	**	***	***	***	*	***	***	***	35
8	Keefe-Cooperman 2005	*	***	*	**	*	**	**	*	**	*	*	*	**	***	33
9	Burgoine et al 2005	*	***	**	*	*	***	**	**	**	**	*	**	**	**	26

4.6.1 Selection Methods & Sample bias

None of the studies provided sufficient details regarding their selection or recruitment methods. All of the studies included a clinical sample of women who had undergone a TOPFA, 7 dealt with the psychological impact of TOPFA specifically on women, whereas 2 studies included both men and women, requiring the reviewer to extract details specific to the psychological impact of women. Although all of the women had received a TOPFA, one study split the group to specifically explore the psychological impact of method of termination (Burgoine, Van Kirk, Romm, Edelman, Jacobson & Jenson, 2005), and another compared the impact of TOPFA completed either within the first (weeks 1-12) or second (weeks 13-26) trimesters. For the 7 remaining studies, TOPFA was presented as one large homogenous group, with generally well detailed reports of demographic characteristics across the studies. Authors generally concluded that women representing the TOPFA groups were similar in demographic characteristics frequently being White, well educated women in their early thirties. There was a clear sample bias and obvious lack or representation from black and ethnic minorities and from women of a varied education and age. Where a control group was present (Kersting et al, 2005, 2009), they were often a poor match, having significant variations in age, number of living children and education levels, thus undermining ones confidence that differences in psychological outcomes were as a result of experiencing TOPFA.

The reporting of participant response rates was generally found to be poor with only 4 studies providing details on the proportion of those who were asked to participate and accepted (Korenromp et al, 2005; 2005; 2007; 2009). Between these studies, the percentage of participant responders was generally found to be between the second and third quartile (54-79%), indicating that a significant proportion of the sample were not being represented. However, Korenromp et al (2005; 2005; 2007; 2009) compared non-participants with participants' on factors such as duration of pregnancy at termination and assessed viability of the disorder, finding no significant differences between the two groups. In order to ensure that the participant characteristics are representative and in order to minimise bias, studies should at least report details pertaining to uptake and ideally explore any differences between non-participants and participants as this would have significant implications for the generalisability of their findings.

The reporting of comparisons between full participants and those lost to follow-up generally fared better with 8 studies reporting attrition rates with 5 also providing evidence of comparisons between full participants and those lost to follow up.

4.6.2 Design Biases

The studies included in this review are composed of cohort, cross sectional and case-controlled designs. The two cross sectional studies (Korenromp et al, 2005; 2005) were designed to investigate the psychological consequences of participants between 2 and 7 years post TOPFA. This cross-sectional sample provides us with a snapshot of women following TOPFA, at that one point in time. This is useful in measuring the prevalence of psychological difficulties, but does not tell us if these difficulties changed with time. There was a distinct absence of appropriate control groups which would have helped strengthen the cohort design and allowed better comparisons. Where control groups did exist, they often differed on important factors other than TOPFA (i.e. number of living children) adding an additional source of bias.

Designs frequently failed to account for confounding variables. Obvious confounds such as premorbid psychological functioning was only addressed in two studies (Korenromp et al, 2007; Kersting et al 2009), who reported having included The Generalised Self Efficacy Scale (SES; Wegner, Schwarzer & Jeruzalem, 1993) and The State-Trait Anxiety Inventory (STAI; Speilberger & Gorsuch, 1983) respectively, as measures of stable personality characteristics. Furthermore, none of longitudinal studies controlled for changes to participants circumstances as a result of other recent traumatic life events which might have occurred after initial data collection (e.g. other traumatic experiences).

4.6.3 Statistical Analyses

All of the studies employed a correlation or regression based analysis, with the exception of Davies et al. (2005) who compared the psychological impact of first trimester TOPFA with second trimester terminations using Crude Odds Ratios. The latter study reported confidence intervals, however they were noticeably large, jeopardising the reliability of their findings. The studies which used regression methodologies had validated psychological measures as dependent variables and although neither correlation, nor regression methodologies can substantiate causation, this was frequently implied without discussion of potential third (unidentified) variables. Given the difficulties in employing such methodologies within this area of research, it is imperative that authors control for variables that are known to effect psychological functioning. Failing to control for certain variables (e.g. premorbid psychological functioning and additional traumatic events) within

correlation or regression methodologies significantly jeopardises the internal validity of these studies.

Only one study reported using post-hoc corrections (Tukey's HSD or Bonferroni tests where appropriate) despite most studies including multiple analyses, increasing the risk of Type I errors (Kersting et al, 2005). Additionally, a number of studies report the significance of individual coefficients within a model, making it subject to error-inflation and increasing the likelihood of finding an erroneous significant effect. That said, the case for correction is controversial and as the included studies are exploratory, there is an argument that the authors should focus on minimising Type 2 (rather than Type 1) errors, and so avoid adjustments (Goeman & Solari, 2012). Despite this topical argument, the studies scrutinised here were appraised according to convention, as the authors did not offer the results as exploratory rather as absolute findings. Furthermore, there was a tendency for small but significant 'R' values to be reported without explicit reference to effect size, potentially misleading the reader. Additionally, one of the primary authors, Korenromp et al (2005, 2005, 2007, 2009) appeared to routinely report (*p< 0.10 (trend)) trends in the data. This is unusual and given that individual coefficients from within the regression model were often reported without correction, this substantially increases the risk of familywise error.

5. Discussion

Results from the review of this literature emphasised that the experience of terminating a pregnancy for fetal abnormality is often characterised by poor psychological outcomes. Research on the TOPFA so far have employed heterogeneous methodologies and reported heterogeneous results making it difficult to integrate their findings and come to a full understanding of the prevalence, nature and longevity of psychological problems.

As with previous research, almost all authors found evidence of pronounced feelings of grief in the initial period after TOPFA (Black, 1989; Hunfield et al., 1997; Iles & Gath, 1993; Salvasen et al., 1997; White Van Mourick, et al., 1990). Discrepancies between current studies regarding the long-term effects of TOPFA were found. Unlike previous research where distress decreased in the first few years post event (Black, 1989; Hunfield et al., 1997; Iles & Gath, 1993; Salvasen et al., 1997; White Van Mourick, et al., 1990)., the largest case controlled study to date found no significant difference between women 2-7 years after TOPFA and those 14 days after with respect to grief and PTS symptoms (Kersting et al., 2005). The findings from this study benefit from the improved statistical

power that their large sample size offers, however huge attrition/ response rates (49%) were observed which may indicate that non-responders were either unable to due to increased suffering or unwilling to do so because of adequate coping, either possibilities limit confidence in their conclusions.

Perhaps most revealing was the findings that post traumatic stress symptoms stood out from all other psychological reactions in terms of persistent prevalence, indicating that the distress associated with TOPFA is characterised by a number of cognitive processes. High scores on measures of post-traumatic stress symptomology highlight the role of higher-order mental processes (Horowitz, 1976; Horowitz et al., 1993; Parkes, 1971) such as intrusive thoughts and hallucinations that appear to maintain current feelings of distress. By exploring associations between outcome measures and factors believed to impact on level of distress, it emerged that symptoms of PTS were strongly associated with factors such as gestational age at TOP and levels of partner support. Such information is important as it provides evidence that early diagnosis and consistent support are of high importance (Statham, 2000). Scores on PTS, unlike all other outcome measures, did not appear to relate to measures of generalised self-efficacy, indicating that the higher order mental processes involved in PTS are not associated with perceived self confidence in one's ability to cope. Given the significance of PTS post TOPFA, future research into this apparent distinction would be useful.

The differential course of symptoms of both depression and anxiety may well reflect the different points at which women enter the phase of re-integration. Overall symptoms of anxiety and depression lessened with time. One explanation is that with time women move away from the narrow repertoire of passive behaviour that they developed in order to avoid the aversive experience of TOPFA and begin to develop new patterns of behaviour, engaging more frequently in pleasant and satisfying activities and obtaining more positive reinforcement than they had in the immediate aftermath (Veale, 2008). This would also help explain why scores on depression and anxiety appeared to increase briefly around the anniversary of TOPFA.

The current finding that low level of education was associated with worse outcomes does not support previous research with women following TOPFA, which indicated that level of education or socio-economic status was not associated to psychological outcome (Black, 1989; Zeanah et al., 1993). However, research findings from normal pregnancies suggest that higher educated women make better use of available coping mechanisms (Huizink, et al., 2002).

Increased psychological distress in terms of grief and PTS was found to be associated with advanced gestational age. This finding is consistent with previous research which suggests that terminations occurring later in pregnancy result in diminished coping (Black, et al., 1989; Salvasen et al., 1997, Posavac & Miller, 1990). Archer (1998) suggests that we should expect an overall increase in grief with the length of the pregnancy including a stronger grief reaction as the mother's age increases. This point is interesting in that it reflects the view of Bowlby (1969, 1973) in his writings on attachment, separation and grief reactions. Furthermore, a woman's inner experience may involve a developing attachment that strengthens with each day, based on their plans and hopes for their babies' future (Peppers and Knapp, 1980). This highlights the point made by generic models of grief, that it may be the discrepancy between their inner experience, their hopes and plans, and the harsh reality of their outside world having experienced a TOPFA that evokes intense psychological distress, rather than a loss defined in any objective terms (Parkes, 1971; Archer, 1998).

Correlation values for partner support as associated with different psychological outcomes were extremely high in all cases. This finding is highly consistent with previous research in which there is a well established relationship between perceived levels of support and psychological suffering, where individuals who perceived good partner support fared better (Black, 1989; Statham, Solomou & Green, 1999).

The finding that religiosity was associated with increased levels of psychological distress following a TOPFA was not discussed by any studies in depth. Previous research has shown that religion, especially intensity of involvement, is associated with attitudes toward possible reasons for termination. Harris and Mills (1985) suggest that a termination in response to physical considerations ("hard" reasons - birth defect, threat to mother's health, rape) differs substantially from acceptance of social considerations ("soft" reasons - not wanting more children, not able to afford more children, not wanting to marry). They propose a theory of 'value conflict' which argues that physical and social reasons evoke conflicting values of self determination and responsibility for others. They describe how these values are differentially reinforced both by religious groups and by the level of involvement with religion. It is therefore this "elective affinity" between values and abortion reasons that not only explains part of the empirical relationship between religion and attitudes but also suggests an intervening mechanism by which religiosity influences decisions regarding abortion and potentially psychological outcome following the decision made.

All studies had a major weakness, namely that they did not include measures of stable personality traits and coping styles. Findings from abortion studies suggest that influences such as poor emotional adjustment prior to pregnancy, poor coping with stressful events in general, perceiving others as unsupportive and uncooperative, and uncertainty regarding their decision to terminate a pregnancy all increase levels of distress and hinder adjustment after the abortion (Harris, 1986; Major et al., 1990; Major and Cozzarelli, 1992). As such, coping styles and premorbid psychological functioning should clearly feature within future studies design.

Finally, it is important to recognise the limitations of attempting to integrate findings from varied methodological sources. Although critical appraisal has been attempted, development of a new tool to reflect the different methodological approaches of included studies is in and of itself problematic. Lack of confidence in the proposed appraisal tool comes from an awareness of the importance of validity and reliability in such tools.

6. Conclusion

Discrepancies between the included studies in terms of; their findings, measures identified as demonstrating the poorest outcomes, and their discovery of, and emphasis on factors associated with better or worse outcome, serves to highlight the intricate and diverse nature of a woman's experience.

This review has highlighted the most common psychological outcomes following TOPFA and despite the lack of controlled studies aimed at directly investigating which factors appear to increase/ reduce levels of psychological morbidity, it has summarised those factors which appear best related. The dearth of hard data reflects the numerous difficulties involved in attempting prospective research in an area as sensitive as TOPFA. To begin, the researcher must consider the ethical issues involved in collecting data during an emotionally laden event; second, there are few models available to provide guidelines for this type of research. As a result of these difficulties the majority of studies evaluating the psychological impact of TOPFA have used retrospective interview formats. More longitudinal prospective studies are needed, particularly ones which explore the impact of coping style on long term psychological outcome.

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Appendix I: The following search strategy was entered into Ovid interface including Medline, Embase and PsycINFO databases.

	Search Terms	**Results**
1	Fetal fetal abnormalities {No Related Terms}	1221
2	exp congenital abnormalities/	813678
3	Fetal Fetal anomalies {No Related Terms}	52925
4	exp congenital defects/	5593
5	1 or 2 or 3 or 4	858763
6	exp Abortion, Legal/ or abortion.mp. or exp Abortion, Spontaneous/ or exp Abortion, Therapeutic/	87716
7	termination.mp.	70178
8	exp Bereavement/	15488
9	exp Fetal Fetal Death/	27729
10	6 or 7 or 8 or 9	188160
11	Psychological impact.mp.	4171
12	psychological consequence.mp.	75
13	exp Stress, Psychological/ or psychological morbidity.mp.	55309
14	exp Grief/	18086
15	exp Anxiety/	146889
16	exp Depression/	302552
17	exp Stress Disorders, Post-Traumatic	29234
18	exp Adaptation, Psychological/	43849
19	coping.mp.	108339
20	11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19	608737
21	5 and 10 and 20	549
22	remove duplicates from 21	534
23	limit 22 to english language	496
24	limit 23 to peer reviewed journal [Limit not valid in Ovid MEDLINE(R) Daily Update, Embase; records were retained]	490
25	limit 24 to yr="2000 -Current"	355

Appendix II: Table 3: Quality assessment tool: Adapted from CASP (2006) case control/ cohort study quality checklist & SIGN'S appraisal checklist for case control/ cohort studies.

		Quality Control	Rating Criteria
Design	1	Did the study have adequate power to demonstrate effect?	***Adequate power calculations were completed and reported; **Power calculations were reported but power was insufficient; *There were no reports of power calculations
	2	Was there a control or comparison group?	*** There was a comparison group allowing reasonably specific conclusions to be drawn ** There was a control group but it only allowed general conclusions (e.g., healthy controls); * There was no control group or their data was not analysed.
Participants	3	Were the groups matched Demographically?	*** Reported demographic variables were matched; ** Some demographic characteristics were un-matched or data was reported without statistical comparison. Any differences were corrected in subsequent analysis; * The groups differed in several ways that were not statistically corrected or there was no data.
	4	Did the study indicate how many of those asked to take part did? In each of the groups being studied?	***Data pertaining to take-up rates (and any differences between groups) recorded and >75%; **The study describes take up rates (and any differences between groups) take up is <75%; * The study describes take up rates (and any differences between groups), take up is <50% or there is no reference to take-up rates.
	5	Was the likelihood that some eligible subjects might have psychological problems at the time of enrolment assessed and taken into account in the analysis?	***Data available from direct measures of psychological health (i.e. trait anxiety) before TOPFA using a valided tool; **Data available for lifetime diagnoses or through self report; *No mention of premorbid psychological functioning.
	6	What confounding factors have the authors accounted for? (i.e. other recent traumatic life events) Have they taken into account potential confounding factors in design and analysis?	***Potential confounds are identified and incorporated into design and analysis; **Potential confounds are identified and corrected for in analysis; *Identification of potential confounds are either; only discussed, or completely absent.
	7	Is the follow-up of participants nearly 100% complete? Is the attrition rate communicated?	*** Evidence of low attrition; **Evidence of medium attrition; *No attrition rates reported/ calculated or high attrition.
	8	Were comparisons made between full participants and those lost to follow up?	***Information reported on details of drop-outs and comparisons made; **information reported on details of drop outs, no comparisons made; *no details on those lost to follow up

Assessments	9	Was grief and post-traumatic stress assessed using a validated measure?	*** Both grief and post-traumatic stress were assessed; ** either grief of post-traumatic stress were assessed; *Neither grief or Posttraumatic stress were assessed
	10	Were depression and anxiety measured?	*** Both depression and anxiety were assessed; ** Either depression or anxiety were assessed;*Neither depression or anxiety were assessed.
Statistics	11	Was a correction applied to take multiple comparisons into account?	*** A Bonferroni (or other) correction was applied; ** A more conservative p value was used (p<.01); * No correction was used, p remained .05
	12	Were effect sizes adequately reported?	***All effect sizes were reported **Some effect sizes were reported *effect sizes were not reported
	13	Were statistical technique(s) used to take into account or control for potential confounding variables?	***Confounding variables were identified and statistical techniques employed to account or control for confounds; **Confounding variables were discussed but statistical correction was not employed; *Potential confounds were not discussed.
Obstetric Data	14	Were details of affected pregnancy reported? (Maternal age/ Gestational age at time of TOPFA, Method of termination, agency in decision to terminate)	*** Information for all identified variables was given; ** Some information about Participants' obstetric characteristics was given; * Very little or no information regarding obstetric characteristics was provided.

Appendix III

This review has been prepared for The British Journal of Obstetrics and Gynaecology. This journal was chosen for pragmatic reasons in that the review corresponds with its stated areas of interest.

BJOG welcomes submissions of papers on all subjects relating to women's health. We give priority to papers containing original data, systematic reviews and commentaries suggesting innovative approaches to women's health problems.

Topics of interest to the journal include; psychological, behavioural, cognitive, affective, dynamic, medical, societal and social aspects of: fertility and infertility; menstruation and menopause; pregnancy and childbirth; antenatal preparation; motherhood and fatherhood; early infancy; infant feeding; early parent-child relationships; postnatal psychological disturbance and psychiatric illness; obstetrics and gynaecology including preparation for medical procedures; psychology of women; nursing, midwifery, neonatal care, health visiting, health promotion and health psychology.

The extensive guidelines for authors can be found at:

http://www.bjog.org/view/0/authorInformation.html

Psychological coping following pregnancy termination for fetal abnormality

Thesis Abstract

Objectives: We examined the psychological consequences of termination of pregnancy for fetal abnormality (TOPFA). The impact of individual coping styles as well as a number of obstetric factors were assessed to determine their relevance in relation to the psychological impact of this event Additionally, when faced with health related decisions, individuals will have an idea about the level of input or control they wish to take (control preference).We aim to explore whether disparity between an individual's control preference and their perceived levels of control in relation to a) their decision to terminate and b) by which method increased their levels of distress.

Design, Setting & Sample: A cross-sectional cohort study was performed on a community sample of 122 women who had terminated a pregnancy for fetal abnormality.

Methods & Outcome Measures; The construct of control preference for health related decisions was assessed in the context of a TOPFA. This, obstetric factors, social support, and coping style (predictor variables) were used to investigate psychological outcome on standardised questionnaires which measured depression, anxiety, grief, and post-traumatic symptoms. Four parallel hierarchical regression models were developed.

Results: Termination of pregnancy for fetal abnormality is associated with a range of symptoms on standardised measures of psychological morbidity. Clinically relevant determinants included social support and a range of coping styles, namely: denial, behavioural disengagement, self-blame and acceptance (protective).

Conclusion: Coping is a psychological construct of significant importance within the context of TOPFA. Behavioural disengagement, denial and self-blame all predict worse outcome. In contrast good social support and coping through acceptance predict better outcome on standardised questionnaires which measured depression, anxiety, grief, and post-traumatic symptoms.

Keywords:
Termination of pregnancy; Fetal Abnormality; Psychological sequelae; Depression; Anxiety; Grief; Post-traumatic Stress; Coping and adaptation, Control Preference health decisions; Hierarchical multiple regression.

1.0 Statement of Contribution

In completion of this thesis the majority of responsibility pertaining to project design, applying for ethical approval, writing the review of the literature, recruiting participants, designing the online survey data collection tool, analysing the data and writing up has lain with the trainee clinical psychologist. Advice regarding the project design, literature review, recruitment of participants, analysis of data and write up was given by the research supervisor, Dr. Nima Moghaddam.

External clinical research supervision regarding the research design, literature review, recruitment of participants and development of the study protocol was provided by Dr Helen Statham.

Summative feedback regarding the study design, applying for ethical approval, revising the literature review and analysing data was also given by the academic research staff on the Trent Doctorate in Clinical Psychology, namely; Dr Roshan Das Nair and Dr Mike Renoldson through their examination and feedback of the original research proposal (RED).

Regarding recruitment of participants and by providing a service user's perspective on the design and language used within the online survey, the assistance of the staff at Antenatal Results and Choices (ARC) was invaluable. Special thanks go to Jane Fisher and Helen Statham for their support, time, advice regarding ethical considerations, and overall encouragement in completing this project.

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A special thanks to my family; you gave me strength when I was tired, you always believed in me, and provided patience, compassion, and support when I needed it most. To my husband and son; Graham, Harley, I love you to the moon and back.

Finally, thank you too all of the courageous women who shared their profoundly powerful experiences with me and for making this study possible.

Psychological coping following pregnancy termination for fetal abnormality[1]

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Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

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[1]For submission to BJOG: An International Journal of Obstetrics and Gynaecology (see opening paragraph of extended paper. Author's guidelines are available from: http://www.bjog.org/view/0/Manuscriptlayout.html (please note the journal paper was prepared based on the 5000 word limited which has recently changed.)

Journal Paper Abstract

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4.0 Introduction

Over the past decade, technological advancements in screening and diagnostic measures have resulted in improved early detection of fetal abnormalities. Detection of a severe congenital abnormality gives rise to a series of time nested and time-sensitive decisions[1], in which the majority of couples opt for termination.[2,3] This has led to an increasing number of terminations of pregnancy for fetal abnormalities (TOPFAs), currently around 47 per 10,000 total births in the UK.[4] Furthermore, these figures are likely to dramatically underestimate the prevalence of TOPFA as the registers do not cover the whole of the UK.

Factors such as severity of the abnormality and degree of compatibility with extra-uterine life are important considerations in the decision making process[5-7]. Taking the decision to terminate has been described as an 'almost inhuman' thing to have to do[8]. It marks the beginning of a complex and conflicting experience of which little is known about the immediate and long term psychological effects, or the factors which appear to make psychological distress more or less likely.[7,8] Psychological distress predominantly includes (although will not be confined to) depression, anxiety, posttraumatic symptoms and grief. [9-11]

In a review by Wool[11] it became apparent that only a small number of variables have been subject to rigours empirical assessment. Furthermore, the few quantitative studies designed to identify risk factors associated with worse outcome, have produced mixed results. Risk factors believed to affect psychological outcomes (albeit inconsistently) include; gestational age, the type of

fetal abnormality, the method of termination and the degree of social support, particularly that provided by spouses, partners and health professionals.[8, 12-14]

Despite widespread evidence which emphasises the role of coping in adjusting to difficult life events[15,16] there are surprisingly few studies that have focussed specifically on the coping processes involved after a TOPFA.[17] Furthermore, even less is known about the effects of coping strategies on levels of psychological morbidity which we aim to address in this article.

According to Lazarus and Folkman[18] the psychological process of coping is integral to the emotional arousal induced following a stressful encounter. Coping comprises of threat appraisal in which an individual assesses the personal significance of the situation and subsequently draws upon available resources in order to manage the problem. This description highlights two fundamental processes as central mediators within the individual–environment transaction: cognitive appraisal and coping per se. As such, coping consists of appraising the threat in a way that minimises its impact on an individual and potential to cause psychological harm.[19-20]

Dependent upon how an individual personally appraises the stressful event, they will react in a way that is synonymous with their perception. As such, the behavioural and cognitive efforts that they then employ to deal with the situation, can tell us a great deal about the judgements that they have made. A number of competing traditions exist for categorising our coping responses including the longer established problem/emotion focussed[18] and approach/ avoidance

strategies,[21] to the multi-factorial approach[22] and more recently conceptualisations that have settled upon five core types of coping; problem-solving, positive-restructuring, support seeking, avoidance, and distraction.[23] Given that little knowledge exists regarding coping in this context, the empirically supported and comprehensive multidimensional approach proposed by Carver[22] and through use of the Brief Cope, was employed to prevent exclusion of potentially important coping processes.

An individual's appraisal and subsequent coping will be determined by several key personal and contextual factors. Personal determinants might include the individual's expectations, their goals and values and their previous experience. Significant contextual parameters include controllability, predictability and imminence of the stressful event.[20] Previous research has already demonstrated that few women approach prenatal screening expecting a poor outcome, instead believing that the baby will be fine and that prenatal screening is a way of guaranteeing this.[24] Thus, an individual's beliefs and expectation about the likelihood of encountering problems through their own pregnancy could increase their psychological vulnerability in the event of a positive diagnosis.

The contextual factor of controllability is also a relevant field of investigation within the context of TOPFA. Patient preferences for information and decisional roles in the treatment process have focussed mainly on the treatment of oncology patients.[25] The outcome of this work has emphasised the health benefits associated with a more active, participatory role for patients in which they actively influence the final decision of treatment. Little is known about the extent to which

treatment options are made available to women undergoing a TOPFA, or how involved they wish to be in these decisions. The Control Preference construct, developed from work with cancer patients is defined as “the degree of control an individual wants to assume when decisions are being made about medical treatment” [26 (pp1)] and formed the premise of the Control-Preferences Scale (CPS[26]). Originally developed to measure a construct that emerged from a grounded theory of how treatment decisions are made among people with life-threatening illnesses, the scale was developed to elicit consumers’ preferences concerning their contribution in health-care decisions It was originally developed as a card sorting technique with pictures describing the different roles the patient and doctor can assume in medical decision making, but today data collection varies. The possible responses range from the individual making the treatment decision alone, through the individual making the decision jointly with the physician, to the physician making the decision. It has been adapted in this study to take account of how involved women generally like to be in making health-care decisions, and how involved they actually felt with regards to their decision to a) terminate, and b) by which method. By studying the degree to which the women’s actual involvement, met with their preferred levels of involvement (control preference) we hope to determine whether controllability has an impact on psychological outcome.

The current study integrates evidence from qualitative studies and considers how the inclusion of important psychological and theoretical assumptions relevant to coping and decision making can help to strengthen our understanding of psychological morbidity following a TOPFA. Statham[6 (p732)] has alluded to the need for more investigations of the kind as she writes, “Many studies have described

the distress, but few have measured it in any formal way with a view to answering specific questions with a clinical relevance."[6 (p 732)] This study aims to focus specifically on identifying and assessing the impact of moderating factors thought to make distress more or less likely. It makes a unique contribution through its inclusion of measures related to a) match between ideal and actual levels of agency in making important decisions and b) coping responses; whilst re-assessing specific factors previously thought to impact upon levels of distress.

5.0 AIMS

The aims of this study are to answer the following questions;

7. Does type of fetal abnormality and method of termination appear to increase or reduce levels of distress following TOPFA?
8. Does the degree of match between ideal and actual levels of agency in a) the decision to terminate, and b) by which method, influence the extent of psychological distress experienced following a TOPFA?
9. Is perceived satisfaction with social support predictive of psychological outcome?
10. Which coping processes appear predictive of increased or reduced levels of psychological morbidity following a TOPFA?

Specifically, these questions will provide vital information pertaining to a woman's psychological outcome following TOPFA and will help guide clinicians who offer guidance, support and aftercare at this difficult time.

6.0 ETHICAL CONSIDERATIONS

Ethical approval for the proposed study was achieved through the Department of Psychology Ethics Committee at the University of Lincoln (see Appendix 1). [For an extended discussion of the ethical considerations inherent to this study, please see the extended paper].

7.0 METHOD

7.1 Design

The study design was a cross-sectional cohort online survey of women who had terminated a pregnancy due to fetal abnormality.

7.2 Sample

The target sample included women who had terminated a fetus in the second or third trimester due to fetal abnormality. 'Termination', also called voluntary abortion, refers to the removal of an embryo or fetus from the uterus in order to end a pregnancy. 'Fetal Abnormality' refers to a structural or developmental anomaly where there is imperfect embryonic development which deviates from normal, especially as a result of congenital or hereditary defects.

7.2.1 Eligibility Criteria

The Inclusion Criteria included;

- Women who lived within the UK[1] and who had terminated a pregnancy due to fetal abnormality.

[1] The ARC forum provides specialist support for people living in the UK who have lost a baby following a prenatal diagnosis. It is password-protected and moderated by ARC staff. You must be an ARC member to be signed up to the Forum.

And who were,

- Aged 18 or over due to the sensitive nature of the topic.
- English literate
    - The questionnaire was written in English.
    - The Perinatal Grief Scale-33 (PGS-33), Impact of Events Scale (IES) and Hospital Anxiety and Depression Scale (HADS) are all written in English.

7.3 Recruitment

The charity Antenatal Results and Choices (ARC) placed an advert on their website (Appendix 2) directing members to our study link which was located in the member's area of the forum. They also distributed the advertisement of the study within the leaflets and information they provide to new members upon receiving a prenatal diagnosis. ARC is the only charity within the UK which provides non-directive support and information to expectant and bereaved women throughout and after the antenatal screening and testing process. Recruitment through this organisation meant that all of the women who took part in the study were already receiving support from the leading experts.

7.4 Sample Size & Power calculations

Estimated effect-size was based on findings by Kersting[12]; who conducted a regression analysis with IES-R score (14 months post-TOPFA) modelled as a function of multiple predictors (including a combination of obstetric, social support, and psychological variables) and reported a medium-to-large effect-size equivalent to (f2=.23). An a priori power calculation indicates that, given the number of pre-specified predictors variables (22), with an alpha-level set at .05, a

sample size of at least 113 was required to provide sufficient power (80%) to detect an effect of similar magnitude (f2=.23).

7.5 Participants

155 women accessed the online survey, 122 (79%) of these fully completed all of the required questions, with 23 (21%) respondents failing to answer all of the questions. The researchers did not have any requests from participants to have their data withdrawn from the study; in fact they received a number of expressions of gratitude thanking them for the study via email, including requests to hear about the results (see Appendix 4). [For a comparison between those with a complete data set and those who failed to complete all questions please see the extended paper].

7.6 Measures

The first part of the questionnaire contained questions on socio-demographic, medical, and obstetric history which helped define the study sample. It also included a measure of control preference (see below).

7.6.1 Control-preference in health related decisions.

The questionnaire also included items relating to the participants preferred method of making health related decisions and how this compared in relation to their actual experience of the decisions inherent to the decision to terminate a pregnancy affected by a fetal abnormality and by what method. The control preference scale (CPS[26]) was adapted in relation to the event of a TOPFA. Firstly, Participants' were asked to indicate how they prefer to reach treatment decisions in general:

1. *I prefer to make the final selection about which treatment I will receive.*
2. *I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.*
3. *I prefer that my doctor and I share responsibility for deciding which treatment is best for me.*
4. *I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.*
5. *I prefer to leave all decisions regarding my treatment to my doctor.*

Using the same format, they were then asked to indicate their perceived level of involvement in their actual experience of a) the decision to terminate the pregnancy and in b) by which method:

a) In choosing to terminate the pregnancy:
    1. *I made the final decision to terminate*
    2. *I made the final decision to terminate after seriously considering my doctor's opinion.*
    3. *My doctor and I shared responsibility for deciding on termination.*
    4. *My doctor made the final decision about termination but seriously considered my opinion.*
    5. *My doctor made all the decisions regarding my termination*

b) Method of termination:
    1. *I made the final selection about the method of termination*
    2. *I made the final selection about method of termination after seriously considering my doctor's opinion.*
    3. *My doctor and I shared responsibility for deciding which method of termination was best for me.*
    4. *My doctor made the final decision about which method of termination would be used but seriously considered my opinion.*
    5. *My doctor made all the decisions regarding method of termination.*

The participants ideal control preference score as determined by their response on the ideal 'general treatment' rating question was then used as a benchmark in order to determine how well this matched their actual experience in terms of the decision to terminate and the method of termination that was used. As such, two 'difference' scores were produced, these helped determine whether the participants actual experience of making decisions related to termination and subsequent method of termination were supportive of their control-preference for general health related decisions. Higher scores indicated a greater difference between ideal and actual decisional agency. A positive difference score indicated that the participants experienced too much control and decisional agency than they would have ideally liked, whereas a negative difference score indicated that they felt they had received too little decisional control.

7.6.2 Social Support

A number of questions related to the participants perceived level of social support during and after the diagnosis and decision to terminate were included. The Social Support Apgar (SSA[27]) was adapted to measure perceptions of adequacy of social support specific to the event of a TOPFA by asking participants to score perceived satisfaction with five types of support (Adaptation, Partnership, Growth, Affection and Resolve) from seven different sources (the father, my mother, my father, other family, my friends, health professionals and other people I know). For each type of social support, an overall measure representing the average score from the number of different sources available to the person was achieved. Finally, an average of averages computation was performed. This procedure helped to control for the eventuality that certain sources of social support might be absent from an individual's repertoire. [*For a more detailed analysis of perceived support*

in the five distinct areas, please see the extended paper where they are entered into the regression models separately.]

7.6.3 Psychological Coping Style

The Brief COPE[22] (Appendix 6) a self-report inventory was used as a measure of coping style. The measure constitutes 14 subscales: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. In considering their experience of a TOPFA, 28 coping behaviours and thoughts (2 items for each subscale) are rated on frequency of use by the participant with a scale of 1 (I haven‘t been doing this at all) to 4 (I‘ve been doing this a lot).

7.7 Measures of Psychological distress – Dependent Variables

The three dependent variables were scores on self-report questionnaires aimed at identifying a number of maladaptive symptoms that are typically associated with perinatal grief, trauma, depression and anxiety.

7.7.1 Grief

Maladaptive symptoms of grief were measures by The Perinatal Grief Scale Short Version-33 (PGS-33[28]). This is a 33 item scale designed to measures a number of potential reactions to perinatal loss such as grief as a result of yearning for the lost pregnancy and baby. There are three 11 item subscales referred to as: Difficulty Coping, Active Grief, and Despair. Each item is presented as a statement that respondents should rate on a 5-point Likert scale. The scale ranges from 1

(strongly agree) to 5 (strongly disagree) with a neutral midpoint. The 'Difficulty Coping' subscale includes items that indicate depression, social withdrawal, and a difficulty coping with normal routine activities such as ''I feel as though I am just existing and not really living since my baby died''. The Active Grief subscale contains items that reflect expressed grief over the bereaved baby, such as ''I get upset when I think about the baby''. The Despair subscale contains items concerned with feelings of helplessness and hopelessness, like ''I feel worthless since the baby died''. The higher the respondents score the more intense their grief (see Appendix 5). Widely available, the PGS-33 boasts good psychometric qualities and factor structure. In the original research the authors study 138 women; the total instrument had excellent internal consistency with an overall alpha of .92. The alpha of the subscales ranged from .86-.92 and correlates .98 with the long form.[34]

7.7.2 Post-traumatic stress

Symptoms of post-traumatic stress were measured by the revised Impact of Events Scale (IES-R).[29-30] The IES-R is used to assess posttraumatic stress reactions after major life events based on three categories of responses: intrusive experiences, avoidance of thoughts and images associated with the event, and symptoms of hyperarousal. The 22 items are linked to a particular event and assessed according to the frequency of symptoms in the past 7 days on a 4-point measurement scale. The IES is a reliable index indicating the degree of subjective distress associated with a particular trauma providing good psychometric properties[31]. The scale discriminates between a variety of traumatised groups from non-traumatised groups in general population studies. The subscales of avoidance and intrusion show good internal consistency[30, 31]. While related, the

subscales measure different dimensions of stress response. The hyperarousal subscale has good predictive validity with regard to trauma, while the intrusion and avoidance subscales detect relevant differences in the clinical response to traumatic events of varying severity[30]. In our study, as with others, the items of the original scale were anchored to the life event of the termination, as was recommended by Horowitz et al. (1979). (see Appendix 7).

7.7.3 Depression and Anxiety

Symptoms of depression and anxiety were measured by The Hospital Anxiety and Depression Scale (HADS)[32]. The HADS was designed to identify anxiety disorders and depression among patients in non-psychiatric hospital clinics. It is divided into an Anxiety subscale (HADS-A) and a Depression subscale (HADS-D) both containing seven intermingled items (See Appendix 8). The HADS is a much applied and convenient self-rating instrument for people with anxiety and depression in patients with both somatic complaints and mental health problems, and with equally good sensitivity and specificity as other instruments[32]. It comprises a robust factor structure and equally good internal consistency. Cronbachs α has been found to be .78-.93 for HADS-A and .82-.90 for HADS-D, thus the stability of the findings on the internal consistency of the HAD scale support its robustness as a reliable screening tool. There is also good homogeneity of the subscales with individual items loading onto the appropriate subscale and subscales inter-correlating to expected levels.

7.8 Analysis

In order to assess whether: type of fetal abnormality; method of termination; preferred decisional agency; level of social support; and coping style influence the

extent of psychological distress following a TOPFA a three stage hierarchical multiple regression was conducted for each of the three dependent variables; HADS-D, HADS-A, PGS, and the IES. Factors related to Obstetric circumstances were entered as a group at stage one of the regression along with the two scores which represented the disparity between control preference score and actual perceived agency in the decision to a) terminate the pregnancy and b) by which method. An aggregate social support score was determined by computing an average of the scores for each question relating to the different areas (Adaptation, Partnership, Growth, Affection and Resolve). These were entered at stage two along with a measure of the time since termination. Finally, factors related to coping style from scores on the Brief Cope were entered at stage three of the model. All of the above were considered as predictors. The scores on the inventories concerning post-traumatic stress, traumatic grief, and symptoms of depression and anxiety were considered as the outcome measures. The three stage hierarchical model is theory driven and developed from the findings of recent research in this area[2, 8, 10, 11.]

IBM SPSS Statistics 21[33] was used for data management and statistical analysis. Results were summarised with the use of standard descriptive statistics: Counts and percentages for categorical, and means standard deviations (SD), and ranges for continuous variables. A number of parallel hierarchical multiple regression models were developed to account for the different outcome measures. Statistical corrections were not performed. Due to the exploratory aims of the study, the focus was on minimising Type 2 (rather than Type 1) errors, thus avoiding adjustments[34].

8.0 Results

Sample descriptives and correlational analyses are presented to help set a context for understanding the data and inter-dependence of variables before the regression analyses directly address the study aims.

8.1. Sample Characteristics

The results are based on the data of 122 women who fully completed the online assessment and provided full data on all three of the dependent variables, the measures of psychological morbidity. Tables 1 and 2 show the demographic and obstetric characteristics of the participants respectively.

Most participants were in their thirties, were of a White (primarily White British) ethnic origin and were married. The majority of respondents were in full or part time employment and very few participants identified themselves as practicing a religion. Four of the pregnancies were multiple pregnancies (2.9%). The 23 participants who failed to fully complete the online questionnaire did not differ from those that did in all factors measured.

Table 1a –Socio-Demographic Characteristics of the Participants[1].

	Frequency	%
Age categories of participants		
20-24 years	14	9.3
25-29 years	15	9.9
30-34 years	56	37.1
35-39 years	43	28.5
40-44 years	16	10.6
45+ years	7	4.6
Total	151	100.0
Ethnicity		
White British	132	87.4
Irish	3	2
Any other White Background	11	73
White and Black Caribbean	1	.7
White and Asian	2	1.3
Pakistani	1	1.3
Caribbean	1	.7
Total	151	.7
Religion		
Christian	78	51.7
Jewish	1	.7
Muslim	1	.7
Other	3	2
Not Religious	63	41.7
Prefer not say	5	3.3
Total	151	100
Practicing Religion		
Not Religious	64	42.4
Religious but not practicing	48	31.8
Practicing religion	27	17.9
Total (Missing)	139 (12)	7.9
Highest Level of Education		
University Higher Degree	24	15.9
First degree level qualification	61	40.4
Occupational/ vocational	34	22.4
School Qualifications	27	17.9
None of the above	5	3.3
Total (missing)	151	100

[1] Demographic Data collected in accordance with: Statham, H (2002)[43]; Office for National Statistics, (2003)[44]

Table 1b-Relationship & Employment Status Now & at the Time of Termination

	Frequency now	Frequency Then	% now	% then
Relationship Status				
Married	118	111	78.1	73.5
Cohabiting	29	36	19.2	23.8
Divorced/ separated	3	1	2.0	.7
Civil Partnership	1	0	.7	0
Single	0	2	0	1.3
Total (missing)	151	150 (1)	100.0	99.3 (.7)
Employment Status				
Employed Full Time	76	97	50.3	64.2
Employed Part Time	48	33	31.8	21.9
Unemployed Looking	3	3	2.0	2.0
Unemployed Not Looking	20	18	13.2	11.9
Retired	1	0	.7	0
Disabled Not Able	2	0	1.3	0
Total (missing)	151	151	100	100

Table 2 - Obstetric characteristics of the sample.

	Frequency	%
Type of foetal abnormality		
Chromosome Anomaly	8	5.3
Trisomy 13	4	2.6
Trisomy 18	12	7.9
Trisomy 21	37	24.5
Triploidy	5	3.3
Turners Syndrome	3	2.0
Neural Tube Defect	1	.7
Spina Bifida	16	10.6
Anencephaly	7	4.6
Neuromuscular Disorder	1	.7
Isolated cardiac anomaly	5	3.3
Skeletal dysplasia	2	1.3
Other isolated anomaly (hydrocephaly, omphalocéle)	5	3.3
Metabolic Anomaly	1	.7
Multiple Malformation	6	4.0
Other	34	22.5
Unknown	4	2.6
Total	151	100.0
Diagnosed Foetal Abnormality Classifications		
Nervous System (Q00-007)	40	26.5
Other congenital malformations (Q10-Q89)	27	17.9
Chromosomal Abnormalities (Q90-Q99)	72	47.7
Other Conditions (P00-P08; P832-P833; Z80-Z84)	8	5.3
Total (missing)	147 (4)	97.4 (2.6)
Method of termination		
Medical termination	89	58.9
Surgical: Termination	56	37
Method Unknown	6	4.0
Total	151	100.0

8.2. Correlation Analyses

The scores on depression, anxiety, grief and post-traumatic stress, were strongly inter-correlated *(rs.40-.94).* [*Please see extended paper for a more detailed tabulated presentation of these scores].*The means, SDs, and ranges of scores for depression were 8.50 (4.6; 0-21), anxiety 8.90 (5; 0-20), total grief 99 (24; 34-157), and total post-traumatic stress 29 (18; 0-29). These figures are all consistent with previous research, with the range and standard deviations of scores reflecting slightly less variation than previous studies [2,8,10].

Table 3 shows an overview of correlations between predictors and outcome measures. Denial, behavioural disengagement, acceptance, and self-blame (Brief cope) correlated with all of the outcome measures. Other determinants were occasionally related to the outcome measures (Table 3). The type of fetal anomaly, having had a medical termination, and the difference between an individual's control preference score and their actual perception of control in relation to their decision to a) terminate and b) by which method were not statistically related to any of the outcome measures *(ps > .10).* Additionally, three determinants from the Brief Cope (use of emotional and instrumental support, and positive reframing) were not statistically related to any of the outcome measures.

Table 3 – Pearson's correlations between predictor variables and outcome measures

Variable	HADS-D	HADS-A	PGS Total	PGS-A	PGS-DC	PGS-De	IES Total	IES-A	IES-I	IES-H
Congenital Abnormality	.096	.071	.061	.083	.040	.049	.058	.024	.040	.094
Chromosomal Anomaly	.008	.023	.002	-.017	.051	-.036	.067	.058	.102	.000
Nervous System Anomaly	-.117	-.111	-.081	-.112	-.091	-.024	-.151	-.142	-.144	-.103
Medical Termination	.027	.098	-.018	.121	-.058	-.094	.017	-.029	.052	.015
Surgical Termination	.042	.054	.096	.018	.127	.109	.013	.195*	-.106	-.035
Decision to terminate	-.060	.129	.040	.103	.015	.001	.064	.000	.049	.126
Decision method	-.129	-.129	-.118	-.104	-.134	-.088	-.060	-.039	-.080	-.029
Social Support	-.127	-.029	-.154	.006	-.234**	-.176*	-.072	-.224**	.037	-.019
Time Since Termination	-.386	-.394	-.384	-.488	-.338	-.255	-.390	-.160	-.452	-.387
Coping through Religion	.065	.069	.082	.041	.020	.167*	.151	.154	.095	.157*
Self-Distraction	.119	.167*	.156*	.188*	.117	.134	.217**	.211*	.217**	.128
Active Coping	-.204*	-.033	-.169*	-.083	-.175*	-.201*	-.083	-.079	-.077	-.059
Denial	.341***	.346***	.340***	.382***	.276**	.296**	.404***	.285***	.349***	.430***
Substance use	.100	.028	.086	.012	.139	.075	.170*	.169*	.131	.146
Use of emotional support	-.146	-.019	-.014	.070	-.037	-.059	-.018	-.090	.010	.032

Use of instrumental support	-.024	.115	.013	.069	.009	-.037	.057	-.073	.087	.136
Behavioural Disengagement	.514***	.450***	.450***	.396***	.410***	.442***	.426***	.300***	.355***	.473***
Venting	.161*	.352***	.302**	.315***	.247**	.282***	.169*	-.094	.240**	.289***
Positive Reframing	-.086	.014	-.148	-.122	-.153	-.133	.045	-.009	.050	.079
Planning	.073	.223**	.100	.159*	.075	.052	.200*	.083	.212*	.224*
Humour	.142	.094	.048	-.003	.052	.078	.070	-.002	.044	.156*
Acceptance	-.283***	-.179*	-.332***	-.251**	-.317***	-.347***	-.210*	-.217**	-.153	-.188**
Self- blame	.387***	.415***	.575***	.528***	.477***	.596***	.444***	.313***	.413***	.434***

[3]*P < 0.05; **P < 0.01; ***P < 0.00

[3] Due to the no. of correlations, the reader should be cautious not to focus on significance values (due to Type I error-rate). Of more relevance here (essentially pre-cursor analyses for the main regression analysis) are the effect-sizes (i.e., correlation coefficients).

8.3. Hierarchical Regression

Stage 1: Obstetric Variables

None of the outcome measures were independently predicted by any of the predictor variables related to obstetric factors alone (Table 4-7). This included the two scores relating to the how the participants had perceived their 'actual' level of agency in making decisions relating to a) the termination and b) by which method and whether these scores were compatible with their 'ideal' control-preference score for general health related decisions.

Stage 2: Social Support and Time since termination

In stage 2 of the model, dynamic factors related to social support and the amount of time that had elapsed since the termination were entered into the model. Both factors were consistently predictive across all outcome measures. Perceived levels of social support which reflected greater satisfaction, was predictive of reduced scores in PTSD, depression, anxiety and grief *($\beta = 0.34$, $p < .001$; $\beta = 0.28$, $p < .001$; ($\beta = 0.19$, $p < 0.05$; $\beta = 0.34$, $p < .001$ respectively*). Consistently, the factor representing the passage of time since the termination was also predictive of reduced scores in PTSD, depression, anxiety and grief *($\beta = 0.55$, $p < .001$; $\beta = 0.54$, $p < .001$; ($\beta = 0.45$, $p < 0.05$; $\beta = 0.55$, $p < .001$ respectively*).

Inclusion of satisfaction with social support and time since termination in stage 2 of the models increased the amount of explained variance by 16 to 26% as represented by the change in R^2, yielding an overall amount of explained variance ranging from 22 to 30% (Table 4-7). [See extended paper for effects on individual subscales]Although correlations indicated a lack of relationship between some

pre-selected predictor and outcome variables, all predictors will be entered into regression analyses as (1) regression models were planned a priori and (2) there may be suppressor effects such that some relationships are only revealed when variables are modelled concurrently (in regression analyses) versus as zero-order correlations.

Stage 3: Factors relating to coping style

When factors relating to the frequency of use of different coping styles (Brief Cope) were entered in stage 3 of the regression model the predictive utility of the model for each of the outcome variables was significantly improved. Their significance for each outcome variable will be considered in turn.

8.3.1 Post Traumatic Stress

In stage three of the model, Behavioural disengagement *(β = 0.18, p < .001*) and self-blame *(β = 0.42, p < .001* were predictive of worse overall post-traumatic stress.). Acceptance as a coping style was significantly predictive of reduced symptoms of overall post-traumatic stress *(β = -0.25, p< .001).* Inclusion of coping strategies to the post-traumatic stress model increased the amount of explained variance by a significant 33% as represented by the change in R^2, yielding an overall amount of explained variance of 56%.

Table 4 – Results of the hierarchical multiple regression analysis for post-traumatic stress (IES-R)[29-30]

	R^2	ΔR^2	*B*	SE *B*	B
Step 1: Obstetric factors[1]	.030	.030			
Step 2: Social support & TST[2]	.228	.198**			
CPS method of termination			-2.976	1.390	-.185*
Sum Social support			-4.679	1.259	-.344***
How long since termination			-7.617	1.310	-.549***
Step 3: Coping strategies[3]	.556	.328***			
Sum Social support			-2.323	1.050	-.171*
How long since termination			-4.873	1.117	-.352***
Behavioural disengagement			3.726	1.598	.182*
Acceptance			-3.816	1.416	-.253***
Self-Blame			5.006	.894	.416***

*P < 0.05; **P < 0.01; ***P < 0.001

Table Footnote:

[1] Step 1 factors included: Obstetric factors (type of fetal abnormality) and a score to represent the difference between ideal and actual CPS score for a) decision to terminate; b) by which method.

[2] Step 2 factors included dynamic factors: Sum of social support – APGAR scores and a measure of time since termination (weeks).

[3] Step 3 factors included: Scores on the 14 subscales of the Brief Cope: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame.

8.3.2 Depression

In stage three of the model, only the coping strategies behavioural disengagement, planning, and self-blame were predictive of greater levels of depressive symptoms *(β = 0.34, p <.001), (β = 0.22, p = .01),* and *(β = 0.21, p >*

.05), respectively. Inclusion of coping strategies to this model increased the amount of explained variance by 28% as represented by the change in R^2, yielding an overall amount of explained variance of 56 %.(Table 5).

Table 5 – Results of the hierarchical multiple regression analysis for depression (HADS-D)[32]

	R²	*ΔR²*	*B*	SE *B*	B
Step 1: Obstetric factors[1]	0.05	0.05			
Step 2: Social support & TST[2]	0.28	0.23***			
Sum Social support			-0.80	0.26	-0.29***
How long since termination			-1.51	0.27	-0.54***
Step 3: Coping strategies & TST[3]	0.56	0.28***			
How Long Since Termination			-0.96	0.26	-0.34***
Behavioural disengagement			1.39	0.37	0.34***
Planning			0.54	0.27	0.22*
Self-blame			0.52	0.21	0.21

*P < 0.05; **P < 0.01; ***P < 0.001

Table Footnote:

[1] Step 1 factors included: Obstetric factors (type of fetal abnormality) and a score to represent the difference between ideal and actual CPS score for a) decision to terminate; b) by which method.

[2] Step 2 factors included dynamic factors: Sum of social support – APGAR scores and a measure of time since termination (weeks).

[3] Step 3 factors included: Scores on the 14 subscales of the Brief Cope: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame.

8.3.3 Anxiety

In the final model, only the coping styles behavioural disengagement, venting, and self blame were significant predictors of anxious symptoms *(β = 0.24, p .01), (β = 0.22, p = .04),* and *(β = 0.20, p = .02)* respectively. Inclusion of coping strategies to this model increased the amount of explained variance by 29% as represented by the change in R^2, taking the overall amount of explained variance to 52% (Table 6).

Table 6 – Results of the hierarchical multiple regression analysis for depression (HADS-A)[32]

With TST	R^2	ΔR^2	*B*	SE *B*	B
Step 1: Obstetric factors[1]	0.07	0.07			
Step 2: Social support & TST[2]	0.23	0.16***			
CPS method of termination			-0.67	0.32	-0.19*
Sum Social support			-0.58	0.29	-0.20*
How long since termination			-1.37	0.30	-0.45***
Step 3: Coping strategies[3]	0.52	0.29***			
How long since termination			-0.84	0.29	-0.28***
Behavioural disengagement			1.06	0.42	0.24*
Venting			0.62	0.30	0.20*
Self-blame			0.56	0.23	0.22*

*P < 0.05; **P < 0.01; ***P < 0.001

Table Footnote:

[1] Step 1 factors included: Obstetric factors (type of fetal abnormality) and a score to represent the difference between ideal and actual CPS score for a) decision to terminate; b) by which method.

[2] Step 2 factors included dynamic factors: Sum of social support – APGAR scores and a measure of time since termination (weeks).

[3] Step 3 factors included: Scores on the 14 subscales of the Brief Cope: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame.

8.3.4 Grief

Behavioural disengagement, planning, acceptance and self-blame were all identified as significant predictors of grief. Behavioural disengagement *(β = 0.18, p < .001) and* self-blame *(β = 0.42, p < .001) were* predictive of worse overall grief In contrast, acceptance, shared a negative relationship and so was predictive of significantly reduced levels of overall grief *(β = -0.25, p < .001).*

The inclusion of coping styles in the model pertaining to grief, increased the amount of overall explained variance by 36% as represented by the change in R^2 at step 3, yielding an overall amount of explained variance of 66% (Table 7).

Table 7 – Results of the hierarchical multiple regression analysis for grief[28]

With TST	R^2	ΔR^2	*B*	SE *B*	B
Step 1: Obstetric factors[1]	0.04	0.04			
Step 2: Social support with TST[2]	0.30	0.26***			
Diff_ideal_actual_methodterm			-2.98	1.39	-0.19*
Sum Social support			-4.68	1.26	-0.34***
How long since termination			-7.62	1.31	-0.55***
Step 3: Coping strategies[3]	0.66	0.36***			
Sum Social Support			-2.32	1.05	-0.17*
How long since termination			-4.87	1.12	-0.35***
Behavioural disengagement			3.73	1.60	0.18*
Acceptance			-3.82	1.42	-0.25***
Self-blame			5.01	0.89	0.42***

*P < 0.05; **P < 0.01; ***P < 0.001

Table Footnote:

[1] Step 1 factors included: Obstetric factors (type of fetal abnormality) and a score to represent the difference between ideal and actual CPS score for a) decision to terminate; b) by which method.

[2] Step 2 factors included dynamic factors: Sum of social support – APGAR scores and a measure of time since termination (weeks).

[3] Step 3 factors included: Scores on the 14 subscales of the Brief Cope: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame.

9.0 Discussion

In the present study we have assessed the psychological consequences of termination of pregnancy for fetal abnormality in women. To our knowledge, this study is the first to focus on control preference in this context, particularly in relation to experience of distress. Furthermore, it is the first study to directly assess how the use of different coping strategies might be predictive of worse psychological outcome following a TOPFA. Thus, our study findings make a valuable contribution to our understanding of the coping responses of women following this traumatic life event and the potential risks associated with certain strategies over others. We hope that our findings will inform clinical practice and improve the psychological care of women who undergo this procedure.

9.1 Obstetric factors

Like Black[35] and Zeanah et al[36] who failed to find differences between the psychological outcomes of women terminating for different malformations, this study did not find that the different types of fetal abnormality were predictive of increased psychological distress. Nor was the method of termination indicative of increased levels of overall distress. This finding is consistent with that of Zeanah et al[36] and is supported by the later work of Korenromp et al,[8,14] who concluded that the termination procedure did not relate to scores on measures of grief, PTS or psychosomatic complaints. Furthermore, the findings of Burgoine et al[37] who investigated the impact of different methods of termination upon levels of distress, concluded that no significant difference between women who chose Dilation and Evacuation (D&E) or Induction of Labour (IOL) was evident.

9.2 Social Support and Time since Termination

A significant body of research exists to highlight the benefit of social support on health and well-being. Furthermore, a number of studies specific to TOPFA suggest that social support is a vital resource which can help women to adapt psychologically to their loss.[17]. Poor social support has been linked with mood disturbance in women, [38, 8] as well as increased levels of anxiety.[39] Furthermore, provisional attempts at developing models capable of identifying specific risk factors that are indicative of worse outcomes have helped to establish the potential protective qualities associated good social and partner support. Both factors have been linked with better widespread psychological outcomes, including grief, PTS (particularly avoidance and arousal), depression and to a lesser extent anxiety.[8,13-14] In the current study, social support was assessed through the computation of an aggregate score based on an adaptation of the Social Support Apgar.[27] Through this method we were able to demonstrate how perceived satisfaction with social support, being predictive of better outcome, might benefit an individual's overall ability to cope. Furthermore, consistent with theory and empirical investigation, the amount of time since the termination had a significant impact on levels of distress. The more time that had elapsed since the termination, the fewer symptoms were reported. Thus over time, women's mental wellbeing improved.

9.3 Coping

Significant risk factors for poor psychological outcome were coping strategies that included; high levels of behavioural disengagement and self-blame. In contrast, coping strategies high on practicing acceptance of their situation were consistently

predictive of better scores for symptoms of PTSD and grief, indicating a protective element. In a recent study by Lafarge et al[17] Acceptance and Avoidance were both identified as key coping structures. In the current study both denial and behavioural disengagement denote types of avoidance with the latter being consistently indicative of increased symptoms of distress on all of the outcome measures. Qualitative accounts of avoidant coping in women following a TOPFA has helped to explain how women initially engage in avoidant type coping as a way to reduce symptoms of distress, but later realise the detrimental effects of pushing their emotions aside and not working through their grief.[17].

The cross sectional design of this study, revealed how strategies traditionally labelled as maladaptive (behavioural disengagement, self-blame and avoidance) serve to increase levels of distress following a TOPFA. This was true of scores on all of the outcome measures. The findings that avoidant coping is often viewed (at least initially) as a helpful coping strategy[17] reminds us of the risks associated with rigidly classifying coping strategies into discrete categories[22] without reference to their personal and functional properties. Nevertheless, current findings suggest that women would benefit from the knowledge that certain, less adaptive coping strategies, could be less favourable in the long term to more helpful (i.e. coping high in acceptance, reduced self-blame) and empirically supported alternatives.[15,19.]

9.4 Limitations

Firstly it is pointed out with respect to the results presented here that, despite an impressive response rate, the representative nature of the presented results is open to critical discussion. It is arguably important to recognise that the women

represented in this study were recruited though their use of an online support charity and so include women who still identify themselves as requiring support. The outcome of women who are presumably coping better with the loss of their fetus or who do not access online sources of support were therefore not represented. Also, the sample is perhaps to homogenous to be representative, a problem previously found by Black[35]. Finally, large variations were found in the symptoms of grief and post-traumatic stress across the sample. For these reasons the results of the study cannot be claimed to be representative.

Additional factors open to criticism include the possibility of confounding variables; of particular concern is the possibility that additional traumatic experiences or subsequent losses might have influenced responding. Future studies might include objective rating instruments rather than relying on subjective self-report measures to determine psychological morbidity. Finally, the current study failed to incorporate any measures of premorbid psychological functioning, increasing the risk that stable or state personality traits could confound our results.[8,12]

9.5 Clinical implication, future directions & conclusion

Despite the constraints, the results of this study provide the first attempts to investigate whether the level of disparity between a women's control preference for general health related decisions and their actual perceived agency in making decisions in the context of a TOPFA was predictive of psychological outcome. Furthermore it goes some way to demonstrating how the use of certain coping responses might increase the risk of psychological distress.

Self-blame is associated with high levels of shame. It is linked with an increased vulnerability to psychological problems and is known to affect expressions of

symptoms, abilities to disclose painful information, numerous forms of avoidance (e.g., behavioural disengagement and denial) and creates a barrier to seeking help. Several treatment approaches including Compassionate Mind Training (CMT) and Acceptance and Commitment Therapy (ACT) aim to strengthen the affiliative system by developing self-soothing and safeness through self-compassion[41] and acceptance[42]. Such interventions could help women in this context reduce levels of self-blame by helping them to experience feelings of kindness, self-compassion and warmth. Also, by accepting what is outside of their personal control, they learn to overcome their fear of being judged by others, while committing to action that will improve their quality of life[17.]

The current findings also point to the detrimental effects associated with prolonged use of behavioural disengagement and general avoidant type coping. Depressed behaviour, including behavioural disengagement and withdrawal are viewed as a coping strategy to avoid environmental contexts that comprise low levels of positive reinforcement or include overwhelming levels of aversive control. Behavioural avoidance is a key concept to Behavioural Activation (BA) treatment, defined as. "...as a therapeutic process that emphasises structured attempts at engendering increases in overt behaviours that are likely to bring the patient into contact with reinforcing environmental contingencies and produce corresponding improvements in thoughts, mood, and overall quality of life." (p700)[40]. Although there is some evidence that women initially find avoidance helpful, they accept that it also has long term implications particularly by preventing them from working through their emotions[17]. BA uses the collaborative therapeutic relationship in order to help the patient to identify how an internal or external event (Trigger) causes a negative emotional (Response) that signals the start of a recurrent

pattern of avoidance (Avoidance Pattern). It is easy to see how the life event of a TOPFA could result in women experiencing this TRAP[40]. Furthermore, women in this context would arguably benefit from an understanding that avoidance, whilst initially helpful, rarely has long term positive consequences. With this knowledge, BA aims would aim to help the women to reengage in a range of healthy behaviours through the development of alternative more adaptive coping strategies (i.e., TRAC; trigger, response, alternative coping[40]). In view of the significant and consistent impact of coping on experiences of psychological distress, there is a call for the development of improved psychologically informed intervention programs to be evaluated within the context of a TOPFA.

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Extended paper

Extended Background

11.0 Background

11.1 Epidemiology

Approximately 710 000 live births are recorded in England and Wales each year (Office for National Statistics (ONS, 2009), with 4,181 notifications of congenital anomalies (British Isles Network of Congenital Anomaly Registers (BINOCAR), 2011). The prevalence was 206 per 10,000 total births (1 in 49 births). Of the 4,181 notifications of congenital anomalies in 2009, 53% were diagnosed prenatally; giving rise to a series of time nested and time-sensitive decisions (Sandalowski & Barasso, 2005). Figures from the same report suggest that 950 (43%) of these pregnancies resulted in a termination for fetal anomaly. Furthermore, The British Isles Network of Congenital Anomaly Registers (BINOCAR, 2011) state that the overall rate of termination of pregnancy for fetal anomaly was 47 per 10,000 total births; 26 per 10,000 total births before 20 weeks' gestation and 20 per 10,000 total births from 20 weeks' gestation onwards. The highest rate of termination of pregnancy for fetal anomaly was associated with chromosomal anomalies (21 per 10,000 total births), followed by nervous system anomalies (15 per 10,000 total births) and congenital heart diseases (7 per 10,000 total births) (BINOCAR, 2011). The majority of chromosomal anomalies are terminated before 20 weeks' gestation due to screening for Down syndrome, whereas notifications with nervous system anomalies and congenital heart disease are terminated from 20 weeks' gestation as they are structural anomalies which will be primarily detected at the 18+0 to 20+6 weeks fetal anomaly scan (Statham, 2002).

11.2 Psychological impact of prenatal diagnosis

A small number of studies have been conducted with women receiving positive test results, a relatively rare outcome but one that requires more specialised professional intervention. Such research demands special ethical consideration as it is an experience known to elicit overwhelming emotional distress (Statham, Solomon, & Chitty, 2000). Nevertheless, Statham (2002) argues that if we are to appreciate the lasting impact of women's experience of terminating a fetus due to abnormality, it is imperative that research attempts are made, albeit sensitively.

Sandelowski and Barasso (2005) published the first systematic review integrating the findings of qualitative studies of expectant parents living in the United States receiving a

positive prenatal diagnosis. The review retrieved a total of 17 relevant research reports published between 1984 and 2001. Findings indicated that the long-term effects of the couple's decisions were frequently characterised by trauma, devastation and regret, regardless of the exact diagnosis, method and timing of diagnosis, or whether couples ultimately chose to continue or terminate the affected pregnancy (Rillstone & Hutchinson, 2001; Sandelowski & Barasso, 2005; Hunfield et al., 2005). These consequences reflect the seriousness of the life-and-death choices they were obliged to make, choices that are invariably affected by the individuals' attitudes to termination, the supposed certainty of fetal death, their experience with persons with disabilities, past reproductive history, religious orientation and perceived social support (Bryar, 1997; Rillstone & Hutchinson, 2001; Sandelowski & Jones, 1996). Additionally, to a varying degree, the specific diagnosis, input from health care providers, religious outlook, ambivalence about the ability to parent an impaired child, altruistic concerns for the fetus, other children, relationship status, and family life have all been identified as important considerations that complicate our understanding of an individual's experience and unique circumstances (Sandelowski & Barasso, 2005). A major finding of the latter study suggested that the pregnancy outcome (whether or not individual's chose to accept or refuse the option to terminate), had little significance to psychological distress as individual's still felt pulled to make the opposite decision and obliged to justify it to themselves, their families, friends and even to health care providers (Sandelowski & Barasso, 2005).

11.3 Psychological effects of termination

Incidences of complicated grief, depression, anxiety and posttraumatic stress following a TOPFA have been well documented (Davies, Gledhill, McFadyen Whitlow, & Economides, 2005; Kersting et al., 2005; 2009; Korenromp et al., 2007; Green & Statham, 2007).Grief reactions in particular appear to be similar to the characteristics described in the aftermath of other forms of perinatal loss (Salvesen, Oyen, Schmidt, Malt, & Eik-Nes, 1997; Keefe-Cooperman, 2005). However, women who make the decision to terminate a pregnancy are also faced with the moral burden inherent in choosing. Furthermore, research indicates that the chronic nature of symptoms, which have been observed numerous years post-TOPFA, may be what differentiates TOPFA from others forms of perinatal loss (Green & Statham, 2007).

11.3.1 Clinical Psychology and Grief

Bereavement is derived from the Latin word *rumpere* (to rupture, to break, or tear away), and refers to the objective situation of a person who has endured the loss of someone significant. The word 'Grief' stems from the Latin *gra_are* (to weigh down), and refers to the psychological, emotional, behavioural, physical and social reactions to a bereavement. According to Murray-Parkes (2001) following bereavement people will experience a natural 'state of loss' and grief as they adapt to life without the person. Mourning will ensue which relates to the process of psychological adaptation and is characterised by a number of culture based rituals and customs in response to the loss.

Freud's (1957) paper 'Mourning and Melancholia' provided one of the first theoretical accounts of human grieving. Freud claimed that grief had a psychological function that served to protect an individual from emotional turmoil, enabling them to withdraw emotional energy (cathexis), and engage in a process of detachment from the lost loved one (decathexis). The underlying principles to Freud's conceptualisation include the idea that people have a finite amount of energy at their disposal. Consequently, in order to invest in new relationships and activities, they must first release the bound up energy that is consuming them and preventing them from moving forward in their lives. Freud believed that in order for an individual to be freed up from their grief, they must first work through it (grief work hypothesis) by mindfully reviewing thoughts and memories of the deceased (hypercathexis). He recognised that whilst the experience of 'working through' is often a highly painful one, it is crucial in order to achieve detachment from the loved one.

The next theoretical formulation of grief that has influenced our current understanding came from John Bowlby (1980). Bowlby, who is often associated with his work in the area of child attachment, came to highlight similarities between children's reaction to early separation from the mother and the mourning behaviour of adults. Applying an attachment model to grief, he suggests that grief can be best understood as a form of separation distress that initiates attachment behaviour such as crying, searching for the lost person and feelings of anger and abandonment. In contrast to Freud, he believed that the function of these behaviours should be understood by an individual's desire to maintain or preserve attachment and proximity rather than to withdraw from it. Emphasising the survival value of attachment, Bowlby claimed that difficulties arise when the biological function of assuring physical proximity with the loved one can no longer be achieved, like in the case of death. Death presents the bereaved person with a sobering reality in which

they struggle between the disparate impulses of attachment behaviour and the reality that they must survive without their loved one. Bowlby claimed that in order to navigate between these opposing forces, the individual must progress through the following four stages of grief in a seemingly inflexible way:

1. Initial numbness, shock and denial with a sense of unreality;
2. Yearning and protest. It involves waves of grief, sobbing, sighing, anxiety, tension, loss of appetite, irritability and lack of concentration. The bereaved may sense the presence of the dead person, may have a sense of guilt that they did not do enough to keep the deceased alive and may blame others for the death;
3. Despair, disorganisation, hopelessness, low mood;
4. Re-organisation, involving letting go of the attachment and investing in the future as an active life is resumed.

(Bowlby & Parkes, 1970)

Just as Bowlby hypothesised that individuals progress through specific stages in their journey to recovery, many other theorists have also developed stage theories of grief. The influential work of Kubler-Ross (1969) has received much attention and her book 'Death and Dying' borne out of her work with dying patients, outlined the reactions of patients as they face their own impending deaths. She elaborated on Young and Parkes' stages of grief to reflect the five stages of dying experienced by those who were diagnosed with terminal illness:

1. *Denial* the patient does not believe he has a terminal illness.
2. *Anger* Why me? Anger towards family or doctors because they have not done enough.
3. *Bargaining* The patient may bargain with God or some unseen force, to give him or her extra time.
4. *Depression* The patient realises he is about to die and feels very low.
5. *Acceptance* Given the opportunity to grieve, the patient may accept his or her fate, which may lead to a period of quiet reflection, silence and contemplation.

(Kubler-Ross, 1969; Mallon, 2008)

Whilst Kubler-Ross (1969) emphasised that these stages are not linear and that individuals should not be expected to progress through them in a rigid manner, they were

often applied inflexibly, with the different stages being used as a yardstick in order to determine the appropriateness of a person's grieving. In reality, the notion of discrete stages if applied too rigidly to grief is unlikely to fully explain the complex and individualised reactions that people encounter. Some individuals may never reach the point of 'acceptance' or 're-organisation'; some may feel endless anger whilst others maintain a state of denial. Furthermore, empirical studies that have measured coping after loss and produced data on the topic appear to undermine the notion that bereavement and subsequent grief reactions follow a predetermined, universal and orderly path (Wortman & Silver, 1989; 2001; Spiegel & Yalom, 1978; Stroebe & Schut 1999)**.** Instead, they highlight the varied responses that exist and that make grief reactions a highly individualised response mediated by a number of individual, social and cultural differences (Parkes, Laungani and Young (1997).

In moving away from the rigid stage formulations of grief reactions, Stroebe, Schut and colleagues (1993; 1999; 2001) developed the 'Dual Process Model of Grief'. The Cognitive Stress Theory (Folkman, 2001; Lazarus & Folkman, 1984), discussed later in more depth, was pivotal to the development of DPM parameters and the model makes reference to many of the central concepts relevant to coping. The model postulates that stressors in the environment activate the appraisal process which subsequently primes a coping response. If the coping response is appropriate then the outcome is likely to be reflected in good psychological and physical health. In contrast, unhelpful responses will prevent psychological growth and inhibit well-being. The DPM differs from earlier theories through its distinction between two categories of stressors, those that are 'loss' as opposed to 'restoration' orientated. It suggests that individuals oscillate between two grieving processes; 'Loss Orientated Coping' and 'Restitution-Oriented Coping' with the former requiring the person to concentrate on, appraising and working through aspects of the loss itself and the latter requiring the person to adapt and reorient themselves to life without the deceased. Thus, according to this model, the process of accepting a life without the deceased and planning a future separate to the one previously intended reflect restitution oriented coping, an essential component of grieving (Stoebe & Schut, 2000). A final assumption of this model relates to its application: It suggests that different strategies and mechanisms for coping and working through the grief will differ for different people at different times. As such, the authors argue that to understand effective coping, requires a more nuanced approach capable of capturing how different coping strategies function at different times (Schut, Stroebe, de Keijser, & van den Bout, 1997).

11.3.2 Clinical Psychology and Depression

Depression can be defined as a nosological disorder characterised by persistent low mood, absence of positive affect (reduced interest and enjoyment in ordinary things and experiences), and a range of associated emotional, cognitive, physical, and behavioural symptoms that co-occur to form a clinical syndrome, in which day to day functioning is often impaired (American Psychiatric Association (APA), 2000). Frequently depressed individuals will report changes to their sleep pattern, loss of energy, increased irritability, suicidal ideations and feelings of worthlessness and hopelessness about the future (Westbrook, Kennerley & Kirk, 2011).

Becks, Rush, Shaw and Emery (1979) produced a cognitive model of depression which has become highly influential. Centring on the depressive cognitive triad which states that unhelpful thoughts cluster to form negative patterns in relation to; One-self (self-blame, shame, self-criticism), others and the world (nothing ever goes right for me, everyone dislikes me), and the future (I'll never feel better again, It's no use!). Largely with thanks to the impact of Beck's work, Cognitive Behavioural Therapy (CBT) has become the leading treatment approach for depression in the United Kingdom (NICE, 2009). Central to CBT is the cognitive principle which states that people's emotional reactions and behaviour are strongly influenced by cognitions. It proposes that our thoughts, appraisals, beliefs and interpretations about ourselves and the situations we encounter create meaning and that this meaning shapes the way we feel and behave (Westbrook, Kennerley & Kirk, 2011).

CBT recognises that events do not determine emotions, if this were true we might logically assume that a particular event would predictably lead to a specific emotional reaction. We know this not to be the case and CBT posits that 'cognitions' are responsible for idiosyncrasies in the ways we understand and experience an event. Whilst recognising that how we think about situations affects how we feel, CBT also regards behaviour as crucial in maintaining and or shifting psychological states. Following this premise, targeted changes in behaviour are equally popular mechanisms for changing the way someone thinks and feels (Westbrook, Kennerley, & Kirk, 2011).

The CBT model proposes that through experience we develop core beliefs and assumptions about the world which allow us to navigate our way through life with minimal problem. We are all able to function with a mixture of functional and dysfunctional beliefs, and problems only occur when we experience a 'critical incident/s' which contravenes our

core beliefs and assumptions about the world to an extent that our functional beliefs are stifled.

The diagnosis of a fetal abnormality and the subsequent loss of the desired baby following a decision to terminate, symbolises an important 'critical incident'. It challenges the widely held belief and expectation that the pregnancy would be a healthy one, that the baby would be born without serious health concerns, and that the whole experience would be a positive one of parenting a new child and overall celebration (McCoyd, 2008).

11.3.3 Clinical Psychology and Anxiety

The anxiety response is a normal, critical reaction to threat. When a danger or threat is identified, our bodies automatically produce adrenaline in order to primes us for our need to be alert to incoming danger. The classic responses are 'fight' (challenging the fear directly), 'flight' (escaping from or avoiding the fear), and 'freeze' (being physically or mentally immobile). When an incoming threat is perceived, we experience fear and our bodies and mind get ready to deal with it. Difficulties arise when threat systems are activated and individuals do not possess the necessary skills to cope. Evidence suggests that women who have experienced a TOPFA experience high levels of anxiety (Korenromp, 2007, 2009; Kersting, 2009) and may try to cope with the difficult feelings through avoidance (Lafarge, Mitchell & Fox, 2013).

11.3.4 Clinical Psychology and Posttraumatic Stress

The psychological effects characteristic of trauma patients includes a variety of symptoms and behaviours that are subsumed under the diagnosis of PTSD (NICE, 2005). The psychological sequelae characteristic of trauma survivors is often one complicated by coexisting difficulties including anxiety and mood disorders, disturbance in personality, substance abuse and problems managing rage and aggression (Keane & Kaloupek, 1997). Furthermore, the social impact of PTSD, including poor social and occupational functioning, detachment from society and the interpersonal conflict associated with guilt and shame all serve to reinforce feelings of isolation (Kulka et al., 1990).

In a review of treatments for PTSD, TF-CBT and Eye Movement Desensitisation and Reprocessing (EMDR) were recommended (NICE, 2005). According to Ehlers & Clarks (2000) cognitive model of persistent PTSD, symptoms occur as a result of a current threat perception whereby negative appraisals and characteristics of the trauma memory

maintain a sense of threat. How an individual appraises the trauma or sequelae is thought to be at the centre of their experience of current threat. Additionally, their emotional responses are also thought to be linked to appraisals (e.g. responsibility/ guilt). It is the individual's use of inefficient strategies in response to that threat which serves to maintain the problem by preventing change in meaning and memory structures. Avoidance is a common response that maintains traumatic frozen memories which are later integrated into autobiographical memory and updated with current contextual information. Persistent PTSD occurs if the event and its sequelae are processed in a way which produces a sense of current threat (to physical or psychological self). This threat may be from the external world or internal (e.g. threat to view of oneself as a capable person). The trauma memories are re-experienced as if it were happening again and are characteristically; frozen in time, not updated with new information, having no time or meaning context, and are recalled involuntarily.

11.4 Social Support

Social support is an important construct that has been consistently linked with better health outcomes including; enhanced physical health (Bøen, Dalgard & Bjertness, 2012), better well-being and an absence of psychological distress (Finch, Okun, Pool & Ruehlman, 1999; Kessler & McLeod, 1985), and overall improved mental health (Cohen & Willis, 1985; Berkman, 2001; Hefner & Eisenberg, 2010; Hatzenbuehler, 2010). Perceived social support, which is the expectation that family and friends would be available and willing to offer support during moments of need has been linked specifically with less severe symptoms of depression, anxiety and post-traumatic stress (Eldeleklıoğlu, 2006; Brewin, Andrew & Valentine, 2000).

Additionally, it is important to remember that bereavement is a social as well as an individual process. The system around an individual who has experienced a loss can affect it in a number of important ways; if the social support system is perceived positively it can facilitate healing and growth, however, when an individual believes that the wider system isn't a supportive one, or is judging them negatively, then it also has the potential to prevent an individual from coping with their loss (Spiegel, 1993; Kissane & Bloch, 2002).

Current evidence specific to the area of social support after a TOPFA, indicates that there is a protective function to knowing that family and friends are available and can be relied upon at times of great stress. Women who expressed a lack of social support were linked

with increased levels of mood disturbance (Green & Statham, 2007). Additionally, specific measures of partner support suggest that it had an independent effect on levels of grief, post-traumatic stress, depression and anxiety (Korenromp, 2005; 2007). More needs to be understood about the effects of social support on psychological distress following a TOPFA.

11.5 Psychology and Coping

Stress and coping, that is how an individual responds to distressing events and emotions, has been the focus of an extensive amount of research (Carver & Connor-Smith, 2010; Schnider, Elhai, & Gray, 2007). Within the field of psychology, research into the psychological aspects of stress is widespread with coping strategies playing a fundamental role in a person's physical, emotional and psychological welfare particularly in the face of personal challenges, harmful life events and excess stress (Green, 2003).

According to Lazarus and Folkman (1984), Stress Emotion and Coping belong together to form one conceptual unit. They argue that coping is an integral part of the process of emotional arousal in which individuals identify the problem and then evaluate what might be done about it. Thus, the concept of appraisal in which an individual decides on the personal significance of an event in terms of its potential impact on their well-being (primary appraisal), and how they subsequently cope (secondary appraisal) with the demands of the situation (utilizing both cognitive and behavioural efforts) will determine the extent of their psychological distress. In this sense, stress is seen as 'relational' concept that should not be mis-conceptualised as either a specific type of external stimulation or a subjective and explicit pattern of behavioural or physiological responses. Instead, Psychological Stress should be viewed as a 'transaction' between an individual and the parts of their environment that they judge as significant factors for their well-being and in which the current demands exceed the coping resources available to them at that time (Lazarus and Folkman 1986, p. 63). This description highlights two fundamental processes as central mediators within the individual–environment transaction: *cognitive appraisal* and *coping*.

Cognitive appraisals help contribute to our understanding of the individual differences that can be found between the quality, intensity and duration of an elicited emotion, despite the environmental context being objectively equal. As such, appraisals and subsequent patterns of thinking can have substantial influence over how an individual feels, and continues to feel. According to the theory, the content and general flavour of an

individual's appraisal will be determined by several key personal and contextual factors. Personal determinants might include the individual's expectations, their goals and values and their previous experience. Significant contextual parameters include controllability, predictability and imminence of the stressful event.

Lazarus and Folkman (1984) argue that there are three important elements to the primary appraisal which involve the individual making an assessment over the potential impact of the event on their well-being. It is believed that an individual initially evaluates an event in order to determine whether it directly effects the issues that they perceive as important *(goal relevance),* they then make a judgement in terms of the events potential for disrupting their pursuit of personal goals *(goal congruence),* all the time mobilising and accessing aspects of personal commitment, reflecting on their moral values and identity, self esteem and ego-ideal *(ego-involvement*). Equally, three secondary appraisals are defined: initially an individual will apportion *blame or credit* to the persons they deem responsible for the event occurring. They will then embark upon a process of problem solving where they determine which cognitive or behavioural efforts yield the best *coping potential* and function to positively influence their experience of the event. Finally, an individual is required to evaluate their *future expectations* and adjust according to whether the outcome of the event is relatively congruent or incongruent with their future goals. The interaction of primary and secondary appraisals, produce patterns of responding that fall into three broad categories of psychological stress; harm, threat, and challenge. *Harm* encapsulates the cumulative loss or psychological hurt encountered through events that have already occurred, whereas *threat* is in anticipation of that harm. Finally, *Challenge* refers to the demands that an individual believes they can overcome and so they approach them with an expectant confidence in their abilities.

Conceptually, the different categories of psychological stress present alongside a range of patterns of emotional responses to illustrate how stress and emotions co-occur to form *core relational themes*. In our study, the core relational theme of anxiety, might present at the stage of a positive diagnosis in which the women are confronted with certainty and existential threat as the future of the fetus's health is confirmed. At the molecular level the primary appraisal of this situation would determine high levels of both goal relevance and goal incongruence as their desire to have a healthy baby is thwarted (Lazarus, 1991). Additionally, depending on the contextual parameter of 'controllability', we might expect that this situation would elicit a state of helplessness, which too would favour an anxious or withdrawn response rather than perhaps an angry or aggressive one.

Coping is phenomenologically linked to the cognitive appraisal of individual-environment transactions. It is important in the process of dealing with the discrepancy between demands and resources, thus impacting upon and individuals experience of psychological distress. Folkman and Lazarus (1980) classify coping as "the cognitive and behavioural efforts made to master, tolerate, or reduce external and internal demands and conflicts among them (p 223)." This definition is process orientated, it emphasises both cognitive and behavioural responses in an individual in order to stress the importance of classifying coping actions based on characteristics of the coping response, rather than the effect they necessarily have (Lazarus and Folkman, 1984; Folkman and Lazarus, 1980). This theory recognises two broad categories relating to the function of coping, they are; *Emotion-focussed coping,* concerned with the regulation of difficult and painful feelings, and *Problem-focussed coping* which involves targeting the circumstances of the individual-environmental transactions which lead to the distress. In a series of studies executed by Lazarus and Folkman (1980; 1984) to explore the coping processes of both women and men, it was found that both emotion and problem-focussed styles of coping were utilized in 96 and 98% of the cases (Lazarus and Folkman, 1980; Folkman & Lazarus, 1984).

A number of studies have explored coping in parents (particularly women) of children with disabilities (Crinic et al, 1983; McCubbin & Patterson, 1983; Hastings et al, 2005) and with women who have aborted a child for reasons other than a fetal abnormality (Major et al, 1998). However, there exists only one recent study whose primary aim was to explore the coping processes involved in dealing with a TOPFA (Lafarge, Mitchell & Fox, 2013).
Lafarge, Mitchell and Fox (2013), report qualitatively on the coping strategies used during and after the procedure. They analysed the data from the responses of 27 women to an online survey using interpretative phenomenological analysis (IPA). They found that coping consisted of four structures; support, acceptance, avoidance, and meaning attribution, which were consistent across time points, thus reflecting how they coped initially with the procedure, and then afterwards.

Social support was reported as a crucial coping strategy with women highlighting the importance of receiving social support from a variety of resources, these included; Partners (unanimously identified), health professionals, the wider family system, and others more generally. The quality of interactions and support from health care professionals during the termination procedure and beyond was important to the women. They reported that a supportive, empathic style had a lasting positive influence, reducing their levels of distress. In support of this point, some women described being offended by the use of certain diagnostic terms, which they perceived as highly insensitive,

heightening their levels of distress: *"All of her paperwork stated she was a 'nonviable fetus'. I felt she deserved to be recognised...because to us she very much existed. P.S. – Something that really doesn't help is paperwork saying 'non-viable fetus'. Very upsetting to read* (Lafarge, Mitchell & Fox, 2013 p 929*)."* Finally, women identified challenging events that temporarily compromised their experience of social support. Specifically, when friends announced their pregnancies, some women described needing to temporarily withdraw (avoid) from their social network in order to protect themselves (Lafarge, Mitchell & Fox, 2013).

In some instances, women described how the TOPFA represented a practical solution to their problem, maybe representing a type of problem-focussed coping. For others, it was important to focus on the seeking of information (both experiential and factual) regarding the condition and the termination as this was found, for some, to engender a sense of empowerment perhaps akin to the ideas of controllability and predictability described earlier by Lazarus and his colleagues (1980; 1984). This study also revealed how women had described coping with the termination procedure by methods of dissociation. This involved extensive use of self-distraction and by accepting the offer of analgesia with several women reporting that they had used medication to 'disconnect' with the procedure and avoid unnecessary distress. In contrast, one woman described how she avoided the use of pain relief as she perceived the punishing effects of pain to be restorative of the decision she had made. Similarly another woman described the pain as "cathartic" (Lafarge, Mitchell & Fox, 2013).

The use of Avoidant Coping, included; self-distraction, keeping busy (with other children or work), avoiding thinking about the baby, drinking excessive amounts of alcohol (to numb the pain), avoiding pregnant women or women with young children and reframing or rationalising the loss. Although avoidant strategies were initially viewed as helpful, enabling the women to cope, some of the women recognised how their avoidance might have perpetuated the negative emotions that they were feeling. *"Keeping busy and going back to work might have helped initially, but I think they stored up the emotions for later* (Lafarge, Mitchell & Fox, 2013, p 930)". Thus, avoidance was regarded the less homogonous coping structure owing to it including both helpful and unhelpful elements.

This study suggests that the coping responses of women are varied. It highlights how coping with a TOPFA is a personal process, with some coping strategies traditionally viewed as maladaptive, conversely appearing quite adaptive in the context of coping with this kind of loss. Thus, whether a coping strategy is adaptive or not, appears to be a

subjective matter (Lafarge, Mitchell & Fox, 20013; Carver, 1997). Carver (1997) argues that grouping coping strategies into discreet categories i.e. emotional (active/avoidant) and problem-focussed strategies (as with Lazarus & Folkman, 1980; Folkman & Lazarus, 1985) fails to capture the subjective personal processes that are involved for each individual. Instead he recommends examining each aspect of coping independently in order to determine whether how it might be adaptive for one person but not for another.

12.0 Extended Method

12.1 Epistemological position

This study employed a positivist epistemology and posits that reality is stable and can be observed and described from an objective viewpoint (Levin, 1988), i.e. without interfering with the phenomena being studied. A central concept in positivist approaches is empiricism, the theory of knowledge which emphasis's evidence and the scientific method. Empiricism suggests that all hypotheses and theories must be tested against observations. In a positivist view, the world is deterministic, operated by laws of cause and effect in which we use deductive reasoning to postulate theories that we can test.

12.2 Informed Consent

From the survey host (esurv.org, 2003), participants were required to select a box to indicate that they consented to their responses to the survey to be used for the purpose of this research (see Appendix 3).

12.3 Advertisement

Adverts and the survey host displayed the following information:

- Who was conducting and funding the study
- Nature and purpose of the study
- Potential benefits and risks to taking part (emotional impact)
- Right to withdraw
- Option to receive debrief and/ or feedback regarding study findings
- Researcher's contact details
- Complaints procedure

The advertisement contained:

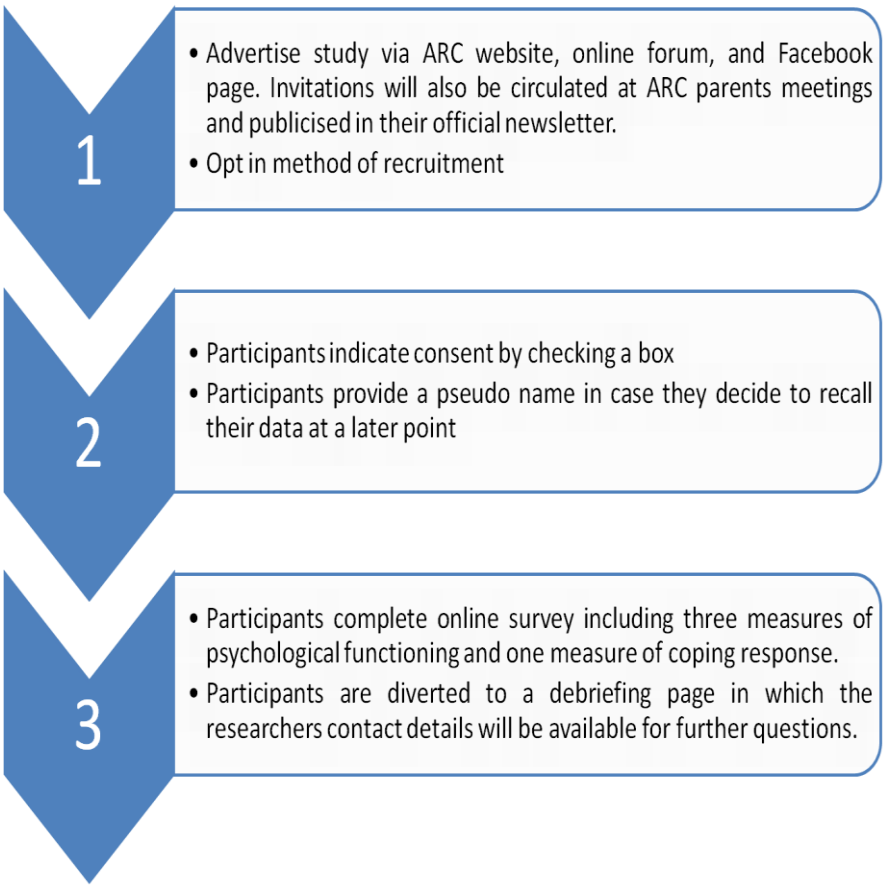
a. Information about the aims and purpose of the study
b. The Inclusion criteria

and

c. Details about what they could expect from involvement

12.4 Procedure

Figure I. This flowchart depicts the procedure that was experienced by each participant. Participants were able to contact the researcher to ask questions about the study, or withdraw from the study up to two weeks after completing the survey.



12.5 Ethics

The target sample was recruited via the leading national charity ARC. This method of recruitment ensured that the women who took part in the study were already receiving support from the leading charity supporting individuals in this situation. Additionally,

participants were advised of the emotive nature of the study and advised of the potential impact that discussing their experiences might have.

Participants were provided with details of the following support networks that they could contact if they become distressed at any point;

- http://www.birthtraumaassociation.org.uk/default.asp
- http://www.babyloss.com/index.php
- http://www.miscarriageassociation.org.uk/

They were also advised that they should contact their General Practitioner (GP) in order to be referred for specific services in order to deal with any distress that they may encounter.

12.6 Steps to anonymise data and protect confidentiality

Participants were asked to provide a pseudo-name that accompanied their data throughout the investigation. By providing a pseudo-name, any participant requesting to withdraw their responses was able to quote this name, allowing the investigator to identify their data whilst protecting their anonymity and confidentiality. Participants were advised that they had two weeks from the completing the survey to withdraw their data. No-one asked for their data to be withdrawn from the study.

13.0 Extended Results

This section of the extended paper documents supplementary tests that were not presented in the journal Paper. These tests support reported results by checking the integrity of the data and by examining the assumptions underlying the analyses conducted. Each of the data considerations and testing procedures reported below were derived with reference to the following texts; Field, (2013), and Tabachnick and Fiddell, (2013).

To assess the accuracy and generalisability of each of the parallel regression models, two sets of tests were carried out. Firstly, diagnostics were conducted to identify the possible influence of multivariate outliers and influential cases. Secondly, underlying assumptions

were checked to determine whether population based conclusions could be supported. For the purpose of demonstrating this process, the regression model pertaining to scores of depression on the HADS will be demonstrated in more detail.

13.1 Diagnostic statistics

Diagnostic testing was carried out to identify cases that may be unduly influencing the regression model (Field, 2013).

- None of the cases had standardised residuals > .2 or absolute values > 2.5
- Values of Cooks distance were all <1
- No leverage values were greater than twice (0.37) or three times (0.57) the average leverage value ((k+1)/n = 23/122 = 0.188).
- Seven values had Mehalanobis distances that exceeded the upper critical value of 38.89 DF26 P=005. The largest value being 53.6
- No values of DFBeta were greater than 1
- All cases had covariance ratio values within acceptable limits (0.75-1.25 for the present data)

From this testing it was possible to conclude that the model had adequate reliability for fitting the observed data and was not overly influenced by a small number of cases.

13.2 Testing of Assumptions

Underlying assumptions were checked to establish the potential generalisability of each regression model. These assumptions and relevant tests are considered below (Field, 2013)

Variable types

All predictor variables were scale or categorical (with two categories), and each of the outcome measures were scale variables..

Independence and non-zero variance

All values of the dependent variables (HADS, PGS-33, IES) came from separate participants, supporting the assumption of independent observations. All predictors demonstrated non-zero variation in value.

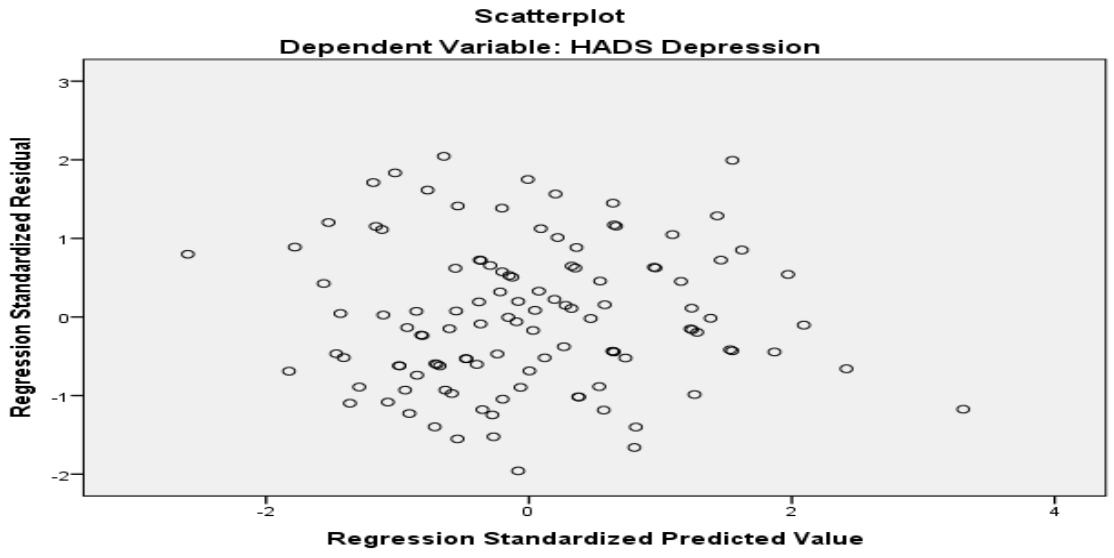
Multicollinearity.

Tables 8-10 show inter-correlation of predictor variables. The highest correlation was in the moderate range (.76), below values suggesting problematic collinearity (.80 and above). Inspection of collinearity diagnostics showed that variance inflation factor (VIF) values were small (1.05-1.25) and within the suggested range of acceptability (i.e.>10) with an average VIF (1.12) was close to 1. Reciprocal tolerance values were all above the recommended lower bound of 0.2. There did not appear to be any problematic collinearly in the data.

Homoscedasticity and linearity

A scatter plot of standardised residuals against standardised predicted values was generated. Inspection revealed a random array of points, evenly spread around the zero line. There was no apparent funnelling or curvature (indicative of heteroscedasticity or non-linearity respectively). It could be concluded that the assumptions of homoscedasticity and linearity were met. Partial plots supported similar conclusion with respect to each of the predictor variables.

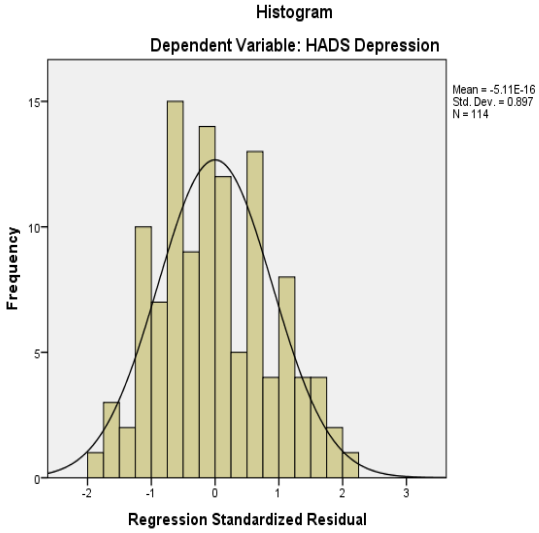
Figure II: Scatter plot of Standardised residuals for HADS-D

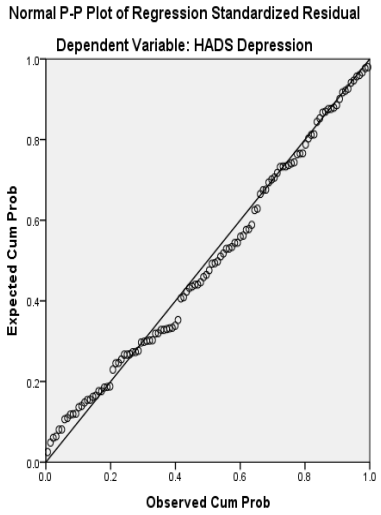


Normally distributed errors

Inspection of a histogram and normal probability plot of the residuals indicated that the residuals were roughly normal: fitting a bell-shaped curve (histogram) and showing little deviation from the line of normality (probability plot).

Figures III & IV Histogram & Normal probability plot of the residuals for HADS-D





Independent errors

The Durbin-Watson statistic for the regression model was 2.045. This was less than the critical value for 22 predictor variables and n=122, indicating that there was no significant autocorrelation among residuals. It could be concluded that the assumption of independent errors was met.

Testing indicated that all the assumptions of regression were met. This increased confidence in the possible generalisability of finding beyond the sample. Validation in other samples would bolster applicability to the population model.

Table 8 Pearson Product-Moment Correlations between obstetric predictor variables entered at step 1 (model one) of hierarchical multiple regression.

	1. Congenital Abnormality	2. Chromosomal Anomaly	3. Nervous System Anomaly	4. Medical Termination	5. Surgical Termination	6. Agency decision to terminate	7. Agency by which method
1	1	-.435**	-.290**	.013	-.028	.109	.075
2	-.435**	1	-.560**	.127	.059	.009	-.052
3	-.290**	-.560**	1	-.152	-.095	-.224*	-.040
4	.013	.127	-.152	1	-.444**	.090	-.141
5	-.028	.059	-.095	-.444**	1	-.013	.216*
6	.109	.009	-.224*	.090	-.013	1	.185*
7	.075	-.052	-.040	-.141	.216*	.185*	1

Table 9 Pearson Product-Moment Correlations between dynamic predictor variables: satisfaction with social support and time since termination entered at stage 2 (model two) of the hierarchical multiple regression.

	1. Diagnosis (Adaptation)	2. Decision (Partnership)	3. Positive Behavioural Change (Growth)	4.Emotional Responsiveness (Affection)	5. Quality of time shared (Resolve)	6. Time Since Termination (TST)
1	1	.691**	.543**	.565**	.642**	-.260**
2	.691**	1	.569**	.565**	.600**	-.353**
3	.543**	.569**	1	.718**	.759**	-.164
4	.565**	.565**	.718**	1	.759**	-.271**
5	.642**	.600**	.759**	.759**	1	-.199*
6	-.260**	-.353**	-.164	-.271**	-.199*	1

Table 10 Pearson Product-Moment Correlations between coping styles predictor variables entered at step 3 (model three) of the hierarchical multiple regression.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Religion	-	.231*	.165	.135	.081	.141	.150	.157	.133	.314**	.198*	.112	.039	.080
2. Self-Distraction	.231*	-	.393**	.135	.149	.287**	.213*	.054	.075	.166	.349**	-.071	.170	.173
3. Active Coping	.165	.393**	-	-.113	-.021	.426**	.339**	-.118	.260**	.359**	.599**	-.047	.607**	-.037
4. Denial	.135	.135	-.113	-	.025	-.034	.071	.394**	.260**	.009	.027	.112	-.225*	.310**
5. Substance use	.081	.149	-.021	.025	-	.127	.155	-.015	.089	-.053	.025	.111	-.009	.128
6. Emotional Support	.141	.287**	.426**	-.034	.127	-	.634**	-.139	.365**	.240**	.473**	-.103	.356**	.089
7. Instrumental Support	.150	.213*	.339**	.071	.155	.634**	-	-.056	.469**	.208*	.470**	-.081	.344**	.127
8. Behavioural Disengagement	.157	.054	-.118	.394**	-.015	-.139	-.056	-	.242**	.005	.023	.270**	-.133	.267**
9. Venting	.133	.075	.260**	.260**	.089	.365**	.469**	.242**	-	.142	.336**	.014	.208*	.364**
10. Positive Reframing	.314**	.166	.359**	.009	-.053	.240**	.208*	.005	.142	-	.451**	.154	.439**	-.047
11. Planning	.198*	.349**	.599**	.027	.025	.473**	.470**	.023	.336**	.451**	-	.011	.466**	.100
12. Humour	.112	-.071	-.047	.112	.111	-.103	-.081	.270**	.014	.154	.011	-	.055	.103

13. Acceptance	.039	.170	.607**	-.225*	-.009	.356**	.344**	-.133	.208*	.439**	.466**	.055	-	-.129
14. Self Blame	.080	.173	-.037	.310**	.128	.089	.127	.267**	.364**	-.047	.100	.103	-.129	-

13.3 Addendum to Journal paper analyses: separate subscale analyses

For the purpose of the journal paper, a three stage hierarchical multiple regression was conducted for each of the three dependent variables; HADS, PGS, and the IES. Factors related to Obstetric circumstances were entered as a group at stage one of the regression along with the two scores which represented the disparity between control preference score and actual perceived agency in the decision to a) terminate the pregnancy and b) by which method. An aggregate social support score was determined by computing an average of the scores for each question relating to the different areas (Adaptation, Partnership, Growth, Affection and Resolve). These were entered at stage two along with the variable Time since termination. Factors related to coping style from scores on the Brief Cope were entered at stage three of the model. The journal paper focussed on the R^2 change for each step of factors (obstetric, social, and psychological) and only reported coefficients for the significant individual predictors. For transparency, the full table including individual predictors at each step of the model irrespective of significance is presented, this helps to illustrate how coefficients shift at each step of the model. The tables containing results of the models pertaining to the HADS-D, HADS-A, PGS-total score and IES-total scores, can be found in Appendix 9 to 12. However the IES and PGS-33 which each comprise multiple subscales, are presented as part of the extended paper allowing consideration of the predictor variables on each distinct subscales of the outcome measures. The results at each level of the model are considered below – with some previously non-significant results appearing better predictors of scores for the distinct subscales.

Stage 1: Obstetric Factors & CPS scores

Neither the type of fetal abnormality, method of termination, or CPS scores for a) the decision to terminate nor b) by which method reached statistical significance as predictors of outcome on any of the measures of psychological distress.

Both stage 2 and 3 of the models included variables that were significant predictors of distress. These will be presented under the specific outcome measures that they relate.

Grief: PGS-33 (Tables 14-16)

Stage 2: Social Support and Time since termination

In addition to the variables entered into stage one of the models, two additional variables was entered at stage two. Both variables, which included the perceived availability of overall social support and the amount of time since the termination were consistently capable of predicting scores on all subscales of the PGS-33. When social support was perceived satisfactorily, it included reduced symptoms of active grief *(β = -0.20, p=.034),* difficulty coping *(β = -0.43, p<.001),* and despair SS *(β = -0.33, p<.001).* The greater the passage of time since the termination the better people was doing in terms of their grief symptoms. This was true on each subscale that comprise the PGS-33*;* active grief *(β= -0.56, p<.001),* difficulty coping *(β = -0.53, p<.001),* and despair *(β = -0.43, p<.001).* Furthermore, with the addition of the two variables entered at stage two of the model, method of termination was now significant for the subscales; difficulty coping *(β = -0.22, p =.028),* and despair *(β-.20, p=.033)* whereby a medical termination over a surgical one indicated reduced symptoms in these areas of grief. Finally, the closer an individuals' level of involvement in the decision about method of termination matched their control preference score, the better they appeared to cope with their grief as determined by scores on the difficulty coping subscale *(β = -0.20, p = 0.18).*

The Inclusion of satisfaction with social support and time since termination in the models increased the amount of explained variance by 17.5 to 26.6% as represented by the change in R^2, yielding an overall amount of explained variance ranging from 20.9 to 32% (Tables 14-16).

Stage 3: Scores on the Brief cope

Scores on the Brief cope were included at stage three of the model. Time since the termination continued to act as significant predictors of scores on all three subscales of the PGS-33: active grief *(β = -0.37, p<.000),* difficulty coping *(β = -0.36, p<.000),* and despair *(β = -0.24, p<.01).* The perceived availability of overall social support was now only a significant predictor of difficulty coping *(β = -0.27, p = .003),* and despair *(β = -0.16, p = .05).* The method of termination also appeared to help predict scores on specific subscales of the PGS-33. Individuals who had undergone a surgical termination had worse scores on the active grief subscale *(β = -0.18, p = .034)* whereas a medical termination was predictive of greater difficulty coping *(β = -0.20, p =.033)* and despair *(β= -0.22, p = .041).*

Of the coping mechanisms measured, self blame was predictive of all of the three subscales that comprise the PGS-33, active grief *(β = .38, p <.000)*, difficulty coping *(β = .38, p = .000),* and despair *(β =.04, p <.000)*. Behavioural disengagement was predictive of difficulty coping *(β = .18, p <.05)* and despair *(β= 0.16, p < .05). A*cceptance as a coping mechanism indicated reduced difficulty coping *(β = -.26, p =.018)* and less despair *(β = -.26, p =.01)*. Finally planning was predictive of active grief (β = .20, p <.05).

The inclusion of coping styles in the models pertaining to grief, increased the amount of overall explained variance by 24.2 to 41.9 % as represented by the change in R^2 at step 3, yielding an overall amount of explained variance ranging from 56.2 to 66.1%.

Post-Traumatic Stress – IES-R (Tables 18-20)

Stage 2: Social Support and Time since termination

The greater the passage of time since the termination the better people was doing in terms of their symptoms of post-traumatic stress. This was true on each subscale that comprise the IES-R; avoidance *(β = -.25, P=. 016),* intrusions *(β = -.55, P<.000)* and hyperarousal *(β = -.49, p<.000).* When social support was perceived satisfactorily, it included reduced symptoms of avoidance *(β = -.29, P=.005)* and hyperarousal *(β = -.22, P =.027).* Finally, medical methods of termination was predictive of less intrusions *(β = -.22, P =.033)*.

The Inclusion of satisfaction with social support and time since termination in the models increased the amount of explained variance by 8.9 to 22.8% as represented by the change in R^2, yielding an overall amount of explained variance ranging from 15.5 to 27% (Tables 14-16).

Stage 3: Scores on the Brief cope

In stage three of the model, time since termination was now only a significant predictor of intrusions *(β = -.30, p <.000)* and hyperarousal *(β = -.27, p =.003).* Social support was a significant predictor of reduced avoidance *(β = -2.3, p =.025).* Surgical methods of termination, was predictive of less intrusions *(β = -0.38 p <.00),* and lower levels of hyperarousal *(β = -0.29, p = .004)* respectively. Medical methods of termination was also

predictive of less intrusions *(β = -.18, p=.042).* Behavioural disengagement was predictive of increased levels of avoidance *(β= .24, p =.019),* and hyperarousal *(β = .24, p = .008)*. Venting, was predictive of reduced levels of avoidant type post-traumatic symptoms *(β= -.34, p=.002).* Planning was predictive of increased levels of intrusions *(β = .30, p =.007),* and greater levels of hyperarousal *(β= .26, p = .021).* Acceptance, was significantly predictive of reduced symptoms of hyperarousal *(β= -.25, p =.021).* Finally, self-blame was predictive of more intrusions and greater levels of avoidance and hyperarousal; *(β= .33, p<.001), (β= .24, p=.017), (β= .27, p =.002),* respectively.

Inclusion of coping strategies to the post-traumatic stress models increased the amount of explained variance by a significant 26.6 to 35.6 % as represented by the change in R^2, yielding an overall amount of explained variance ranging from 42.1 to 57.3%.

Table 14 Summary of Hierarchical Regression Analysis for factors predicting Active Grief as measured by this subscale of the PGS-33 *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*B*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	-0.50	2.90	-0.03	-0.12	2.53	-0.01	0.61	2.16	0.03
Chromosomal Anomaly	-2.22	2.62	-0.15	-2.49	2.31	-0.17	-0.66	2.08	-0.04
Nervous System Anomaly	-2.67	2.85	-0.16	-1.32	2.49	-0.08	-1.60	2.18	-0.10
Medical Termination	2.03	1.65	0.13	-0.79	1.51	-0.05	-0.53	1.31	-0.03
Surgical Termination	2.36	2.55	0.10	0.45	2.27	0.02	-4.27	2.01	-0.18*
Decision to terminate	0.74	0.87	0.09	0.40	0.78	0.05	0.19	0.67	0.02
Decision in method	-0.70	0.51	-0.14	-0.81	0.45	-0.16	-0.01	0.38	0.00
Social support				-0.87	0.41	-0.20*	-0.10	0.35	-0.02
Time Since Termination				-2.53	0.42	-0.56****	-1.67	0.37	-0.37****
Coping through Religion							-0.03	0.33	-0.01
Self-Distraction							0.12	0.35	0.03
Active Coping							-0.34	0.43	-0.08
Denial							0.56	0.59	0.08
Substance use							-0.11	0.40	-0.02
Use of emotional support							0.12	0.38	0.03
Use of instrumental support							-0.43	0.37	-0.11

Behavioural Disengagement			1.05	0.54	0.16
Venting			0.71	0.39	0.16
Positive Reframing			-0.56	0.33	-0.14
Planning			0.80	0.40	0.20*
Humour			-0.68	0.49	-0.10
Acceptance			-0.86	0.47	-0.18
Self- blame			1.50	0.30	0.38****
R^2	**0.059**	**0.300**		**0.636**	
***F* for change in R^2**	**0.951**	**4.952******		**6.826******	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Table 15 Summary of Hierarchical Regression Analysis for factors predicting Difficulty coping as measured by this subscale of the PGS-33 *(N=122)*

	Model 1			Model 2			Model 3		
Variable	*B*	SE	*β*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	1.42	3.55	0.06	1.51	3.04	0.06	2.24	2.89	0.10
Chromosomal Anomaly	0.75	3.21	0.04	-0.52	2.77	-0.03	0.45	2.78	0.02
Nervous System Anomaly	-0.81	3.48	-0.04	0.35	3.00	0.02	-1.14	2.91	-0.06
Medical Termination	-0.61	2.02	-0.03	-4.06	1.82	-0.22*	-3.78	1.75	-0.20*
Surgical Termination	4.22	3.12	0.15	0.87	2.73	0.03	-3.60	2.69	-0.13
Decision to terminate	0.40	1.07	0.04	0.57	0.94	0.05	0.33	0.90	0.03
Decision in method	-1.15	0.63	-0.18	-1.29	0.54	-0.20*	-0.68	0.51	-0.11
Social support				-2.19	0.49	-0.41****	-1.43	0.47	-0.27**
Time Since Termination				-2.91	0.51	-0.53****	-1.98	0.50	-0.36****
Coping through Religion							-0.13	0.45	-0.02
Self-Distraction							0.25	0.47	0.05
Active Coping							-0.37	0.58	-0.07
Denial							-0.74	0.79	-0.08
Substance use							0.50	0.54	0.07
Use of emotional support							-0.17	0.51	-0.04
Use of instrumental support							0.09	0.50	0.02

Behavioural Disengagement			1.46	0.72	0.18*
Venting			0.55	0.52	0.10
Positive Reframing			-0.20	0.45	-0.04
Planning			0.79	0.53	0.16
Humour			-0.27	0.66	-0.03
Acceptance			-1.53	0.63	-0.26*
Self- blame			1.53	0.40	0.32****
R^2	**0.054**	**0.320**		**0.562**	
***F* for change in R^2**	**0.861**	**5.440******		**5.014******	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Table 16 Summary of Hierarchical Regression Analysis for factors predicting Despair as measured by this subscale of the PGS-33 *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	0.36	3.30	0.02	0.43	3.02	0.02	2.07	2.45	0.10
Chromosomal Anomaly	-1.08	2.98	-0.06	-2.01	2.75	-0.12	0.08	2.35	0.00
Nervous System Anomaly	-1.05	3.24	-0.06	-0.18	2.97	-0.01	-0.61	2.47	-0.03
Medical Termination	-1.15	1.87	-0.07	-3.72	1.80	-0.22*	-3.06	1.48	-0.18*
Surgical Termination	2.81	2.90	0.11	0.32	2.71	0.01	-3.62	2.28	-0.14
Decision to terminate	0.19	0.99	0.02	0.31	0.94	0.03	0.74	0.77	0.08
Decision in method	-0.77	0.58	-0.13	-0.87	0.53	-0.15	-0.20	0.43	-0.04
Social support				-1.62	0.48	-0.33***	-0.79	0.40	-0.16*
Time Since Termination				-2.18	0.50	-0.43****	-1.22	0.42	-0.24**
Coping through Religion							0.68	0.38	0.14
Self-Distraction							0.40	0.40	0.08
Active Coping							-0.70	0.49	-0.14
Denial							-0.86	0.67	-0.11
Substance use							-0.09	0.46	-0.01
Use of emotional support							-0.04	0.44	-0.01
Use of instrumental support							-0.39	0.43	-0.09

Behavioural Disengagement			1.21	0.61	0.16*
Venting			0.79	0.44	0.15
Positive Reframing			-0.32	0.38	-0.07
Planning			0.74	0.45	0.17
Humour			-0.20	0.56	-0.03
Acceptance			-1.42	0.54	-0.26**
Self- blame			1.98	0.34	0.45****
R^2	**0.034**	**0.209**		**0.607**	
***F* for change in R^2**	**0.534**	**3.045******		**6.590******	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Table 18 Summary of Hierarchical Regression Analysis for factors predicting symptoms of Avoidance as measured by this subscale of the IES *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	-0.14	0.31	-0.07	-0.16	0.30	-0.07	-0.09	0.30	-0.04
Chromosomal Anomaly	-0.18	0.28	-0.11	-0.27	0.28	-0.17	-0.22	0.28	-0.14
Nervous System Anomaly	-0.37	0.31	-0.21	-0.34	0.30	-0.19	-0.41	0.30	-0.23
Medical Termination	0.07	0.18	0.04	-0.09	0.18	-0.05	0.03	0.18	0.02
Surgical Termination	0.55	0.28	0.22	0.36	0.27*	0.14	0.30	0.28	0.12
Decision to terminate	-0.02	0.09	-0.02	0.01	0.09	0.01	0.04	0.09	0.04
Decision in method	-0.05	0.06	-0.08	-0.06	0.05	-0.10	-0.05	0.05	-0.09
Social support				-0.14	0.05	-0.29**	-0.11	0.05	-0.23*
Time Since Termination				-0.12	0.05	-0.25*	-0.05	0.05	-0.10
Coping through Religion							0.06	0.05	0.12
Self-Distraction							0.04	0.05	0.09
Active Coping							0.01	0.06	0.02
Denial							0.06	0.08	0.08
Substance use							0.10	0.06	0.17
Use of emotional support							-0.01	0.05	-0.03
Use of instrumental support							-0.01	0.05	-0.01

Behavioural Disengagement			0.18	0.07	0.24*
Venting			-0.17	0.05	-0.34**
Positive Reframing			0.04	0.05	0.10
Planning			0.05	0.05	0.12
Humour			-0.09	0.07	-0.13
Acceptance			-0.06	0.07	-0.12
Self- blame			0.10	0.04	0.24*
R^2	**0.066**	**0.155**		**0.421**	
***F* for change in R^2**	**1.063**	**2.112****		**2.884*****	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Table 19 Summary of Hierarchical Regression Analysis for factors predicting symptoms of Intrusions as measured by this subscale of the IES *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*β*	*B*	SE	*B*
Congenital Abnormality	0.08	0.39	0.03	0.14	0.34	0.05	0.11	0.31	0.04
Chromosomal Anomaly	0.12	0.35	0.06	0.11	0.31	0.05	0.24	0.30	0.12
Nervous System Anomaly	-0.25	0.38	-0.11	-0.07	0.34	-0.03	-0.22	0.31	-0.10
Medical Termination	-0.08	0.22	-0.04	-0.44	0.21	-0.22*	-0.43	0.19	-0.21*
Surgical Termination	-0.38	0.34	-0.12	-0.60	0.31	-0.19	-1.19	0.29	-0.38****
Decision to terminate	0.04	0.12	0.03	-0.02	0.11	-0.02	-0.09	0.10	-0.07
Decision in method	-0.05	0.07	-0.07	-0.06	0.06	-0.09	0.02	0.06	0.03
Social support				-0.09	0.06	-0.15	0.02	0.05	0.03
Time Since Termination				-0.33	0.06	-0.55****	-0.22	0.05	-0.30****
Coping through Religion							-0.03	0.05	-0.06
Self-Distraction							0.03	0.05	0.05
Active Coping							-0.10	0.06	-0.18
Denial							0.13	0.08	0.14
Substance use							0.11	0.06	0.14
Use of emotional support							-0.07	0.06	-0.13
Use of instrumental support							-0.01	0.05	-0.01

Behavioural Disengagement			0.09	0.08	0.10
Venting			0.06	0.06	0.10
Positive Reframing			0.00	0.05	-0.01
Planning			0.16	0.06	0.30**
Humour			-0.10	0.07	-0.11
Acceptance			-0.08	0.07	-0.13
Self- blame			0.17	0.04	0.33****
R^2	**0.042**	**0.270****		**0.572****	
***F* for change in R^2**	**0.663**	**4.274****		**5.234****	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Table 20 Summary of Hierarchical Regression Analysis for factors predicting symptoms of Hyperarousal as measured by this subscale of the IES *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*β*	*B*	SE	*β*
Congenital Abnormality	0.12	0.38	0.05	0.16	0.35	0.06	0.17	0.30	0.07
Chromosomal Anomaly	-0.05	0.34	-0.02	-0.10	0.32	-0.05	0.01	0.29	0.00
Nervous System Anomaly	-0.19	0.37	-0.09	-0.05	0.34	-0.02	-0.17	0.30	-0.08
Medical Termination	-0.06	0.22	-0.03	-0.38	0.21	-0.20	-0.25	0.18	-0.13
Surgical Termination	-0.12	0.34	-0.04	-0.37	0.31	-0.12	-0.88	0.28	-0.29**
Decision to terminate	0.13	0.11	0.11	0.10	0.11	0.09	0.04	0.09	0.04
Decision in method	-0.04	0.07	-0.05	-0.05	0.06	-0.07	0.03	0.05	0.04
Social support				-0.12	0.06	-0.22*	-0.05	0.05	-0.09
Time Since Termination				-0.29	0.06	-0.49****	-0.15	0.05	-0.27**
Coping through Religion							0.01	0.05	0.1
Self-Distraction							-0.03	0.05	-0.05
Active Coping							-0.03	0.06	-0.05
Denial							0.15	0.08	0.15
Substance use							0.10	0.06	0.14
Use of emotional support							-0.02	0.05	-0.03
Use of instrumental support							0.03	0.05	0.06

Behavioural Disengagement			0.20	0.08	0.24**
Venting			0.03	0.05	0.05
Positive Reframing			0.02	0.05	0.05
Planning			0.13	0.06	0.26*
Humour			0.00	0.07	0.00
Acceptance			-0.16	0.07	-0.25*
Self- blame			-0.14	0.04	0.27**
R^2	**0.030**	**0.217**		**0.573**	
***F* for change in R^2**	**0.476**	**3.202****		**5.251********	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

13.4 Reworked Regression Models: Separate Social Support

As part of the extended analysis, the three parallel regression models which are reported within the main journal paper were reworked to include separate satisfaction with social support scores in the five distinct areas of; Adaptation, Partnership, Growth, Affection and Resolve (entered at stage 2). This enabled us to assess whether social support in specific areas was more predictive of psychological outcome.

Thus in the additional extended analyses, the hierarchical regression models comprise 26 predictor variables. Estimated effect-size was again based on findings by Kersting et al (2009); these authors conducted a regression analysis with IES-R score (14 months post-TOPFA) modelled as a function of multiple predictors (including a combination of obstetric, social support, and psychological variables) and reported a medium-to-large effect-size equivalent to f2=.23. An a priori power calculation indicates that, given the number of pre-specified predictors variables (26), with an alpha-level set at .05, a sample size of at least 120 will be required to provide sufficient power (80%) to detect an effect of similar magnitude (f2=.23) in the planned study. Once again, for transparency purposes, the full table including individual predictors at each step of the model irrespective of significance is presented.

Table 22 shows an overview of correlations between predictors and outcome measures. Behavioural disengagement and denial (from the Brief Cope) were the only predictor variables to be consistently highly correlated with all of the outcome variables. Time since termination, acceptance, venting and self-blame was also consistently highly correlated with all but one of the outcome measures. Other determinants were occasionally related to the outcome measures. The type of fetal anomaly, having had a medical termination, and the difference between an individual's control preference score and their actual perception of control in relation to their decision to a) terminate and b) by which method were not statistically related to any of the outcome measures ($p > 0.10$). Additionally, three determinants from the Brief Cope (use of emotional and instrumental support, and positive reframing) were not statistically related to any of the outcome measures.

Stage 1: Obstetric Factors

None of the outcome measures were independently predicted by any of the predictor variables related to obstetric factors alone. This included the two scores relating to the how the participants had perceived their 'actual' level of agency in making decisions relating to a) the termination and b) by which method and whether these scores were compatible with their 'ideal' control-preference score for general health related decisions. The score that represented the compatibility between 'ideal' (general control-preference score) and 'actual' perceived level of agency in the decision over the method of termination, showed a trend towards significance (not presented) in two areas; difficulty coping as measured by the PGS, and anxiety as measured by the HADS.

Stage 2: Social support (entered separately) and time since termination

The dynamic predictor variables relating to satisfaction with social support in the 5 areas were entered separately in stage 2 of the model along with 'time since termination'. Social support in each area failed to independently predict psychological morbidity on any of the outcome measures.

In contrast, time since termination was a consistent predictor of outcome across all measures including: Depression - HADS-D *(β = -.52, p <.001)*); Anxiety - HADS-A *(β = -.45, p < .001)*); Grief - PGS-33: ((Active grief *(β = -.55, p <.001);* Difficulty coping *(β = -.50, p < .001);* Despair *(β = -0.42, p < .001));* Post-traumatic Stress – IESR: ((Avoidance *(β = -.25, p = .024);* (Intrusion *(β = -.55, p < .000*); (Hyperarousal, (*β = -.49, p < .001).*

A number of variables relating to the method of termination also increased in their predictive significance. Surgical methods were predictive of reduced intrusions on the IES-R (*β = -.23, p* = .027). Medical methods of termination were predictive of less overall grief *(β = -.20, p = .044), less difficulty coping (β = -.24, p = .018)* and less despair *(β = -.025, p = .020).*

Finally, inclusion of factors at stage 2 of the model increased the amount of explained variance by a substantial 11 to 30.8 % as represented by the change in R^2, yielding an overall amount of explained variance ranging from 17.5 to 36.2 % (Tables 19-29).

Stage 3: Brief Cope

When factors relating to the frequency of use of different coping styles (Brief Cope) were entered in stage 3 of the regression model the predictive utility of the models for each of the outcome variables was significantly improved. Their significance for each outcome variable will be considered in turn.

Depression: HADS-D (Table 23)

The greater the passage of time since the termination, the less depressed participants were as represented by their scores on the HADS-D (*β= -.31, p =.002).* In terms of coping strategies, behavioural disengagement, planning and self blame were all predictive of greater levels of depressive symptoms *(β = .32, p=.001), (β =.23, p=.039), (β =.21, p=.015)* respectively.

Inclusion of coping strategies to this model increased the amount of explained variance by 27.5% as represented by the change in R^2, yielding an overall amount of explained variance of 58.3%.

Anxiety: HADS-A (Table 24)

The greater the passage of time since the termination, the less anxious participants were as represented by their scores on the HADS-A *(β = -.45, p < .001).* In the final model, only the coping styles behavioural disengagement *(β = .0.24, p = .016*) and self-blame (*β = .022, p* = .019) were significant predictors of anxious symptoms.

Inclusion of coping strategies to this model increased the amount of explained variance by 28.6% as represented by the change in R^2, taking the overall amount of explained variance to 52.8%.

Grief: PGS-33 (Tables 25-28)

The greater the passage of time since the termination, the better the symptoms of grief as represented by their scores on all three subscales of the PGS33: ((Active grief *(β = -.36, p < .000);* Difficulty coping *(β = -.33, p < .001);* Despair *(β = -0.24, p = .007)*). Medical methods of termination, were predictive of better coping *(β = -.20, p = .037)* and less despair (*β = -0.19, p = .037*).

Behavioural disengagement, planning, acceptance and self-blame were all identified as significant predictors of grief. Behavioural disengagement was predictive of overall grief (*β = .15, p* = .035) and despair (*β = -0.24, p = .007).* Planning was predictive of active grief, *(β = =.22, p = .036).* Acceptance, being negatively correlated, was predictive of significantly reduced levels of overall grief (*β= -.23, p* = .017), difficulty coping *(β = -.23, p = .035*) and despair *(β = -0.24, p = 022).* Finally, self-blame was predictive of increased levels of overall grief *(β = .41, p = .000),* active grief *(β= .39, p = .000)*, difficulty coping (β = -.33, p < .000) and despair *(β = 0.45, p < .000)*

The inclusion of coping styles in the models increased the amount of overall explained variance by 21.9 to 38 % as represented by the change in R^2 at step 3, yielding an overall amount of explained variance ranging from 58.1 to 67.7% (Tables 25-28).

Post Traumatic Stress: IES-R (tables 29-32)

Social support was not predictive of any scores. The greater the passage of time since the termination, the better the symptoms of post-traumatic stress, with participants reporting significantly less intrusions*, (β = -.36, p = < .001)*, hyperarousal, *(β = -.24, p = .011) and overall post-traumatic stress symptomology (β = -0.27, p = .006) as measures by the IES-R.* Surgical methods of termination, were predictive of reduced levels of overall post-traumatic stress *(β = -.22, p =.027),* less intrusions *(β = -.37, p =.000)* and lower levels of hyperarousal *(β = -.29, p = .004).* Similarly, medical terminations were predictive of reduced symptoms of intrusions *(β = -.21, p =.032).* Substance use was predictive of worse levels of overall post-traumatic stress *(β = 0.18, p = .029).* Behavioural disengagement was predictive of increased levels of overall post-traumatic stress *(β = 0.2, p = .030)*, avoidance *(β = .25, p =.022),* and hyperarousal *(β = .23, p =.013).* Denial was predictive of increased hyper-arousal *(β = .19, p = 0.48).* Venting, was predictive of reduced levels of avoidant type post-traumatic symptoms *(β = -0.36, p < .001).* Planning was predictive of increased levels of overall post-traumatic stress *(β = 0.27, p = .020),* more intrusions (*β= .30, p = .009*) and greater levels of hyperarousal *(β = .27, p = .017).* Acceptance, was predictive of reduced symptoms of hyperarousal *(β = -.24, p = .029).* Finally, self-blame was predictive of increased levels of overall post-traumatic stress *(β= .32, p < .001),* more avoidance *(β = 0.23, p = .022),* and greater levels of intrusions (*β =.32, p* < .001) and hyperarousal *(β = .27, p = .002).*

Inclusion of coping strategies to the post-traumatic stress models increased the amount of explained variance by a significant 26.2 to 35.5 % as represented by the change in R^2, yielding an overall amount of explained variance ranging from 43.7 to 58.3% (Tables 29-32).

Table 21 Pearson Product-Moment Correlations between Outcome Measures of Psychological Distress

Scale	1. HADS-D	2. HADS-A	3. PGS Total Score	4. PGS-AG	5. PGS-DC	6. PGS-De	7. IES Total Score	8. IES-A	9. IES-I	10. IES-H
1	_	.754**	.792**	.692**	.808**	.711**	.681**	.431**	.638**	.715**
2	.754**	_	.755**	.703**	.715**	.697**	.666**	.422**	.623**	.698**
3	.792**	.755**	_	.913**	.944**	.943**	.738**	.499**	.694**	.733**
4	.692**	.703**	.913**	_	.782**	.790**	.688**	.405**	.706**	.668**
5	.808**	.715**	.944**	.782**	_	.848**	.677**	.466**	.614**	.696**
6	.711**	.697**	.943**	.790**	.848**	_	.703**	.523**	.631**	.689**
7	.681**	.666**	.738**	.688**	.677**	.703**	_	.789**	.914**	.905**
8	.431**	.422**	.499**	.405**	.466**	.523**	.789**	_	.525**	.571**
9	.638**	.623**	.694**	.706**	.614**	.631**	.914**	.525**	_	.813**
10	.715**	.698**	.733**	.668**	.696**	.689**	.905**	.571**	.813**	_

* p <0.05 **p < 0.01 ***p < 0.001

Table 22 – Pearson Product-Moment Correlations between predictor and outcome variables.

Variable	HADS-D	HADS-A	PGS	PGS-A	PGS-Di	PGS-De	IES	IES-A	IES-I	IES-H
Congenital Abnormality	.096	.071	.061	.083	.040	.049	.058	.024	.040	.094
Chromosomal Anomaly	.008	.023	.002	-.017	.051	-.036	.067	.058	.102	.000
Nervous System Anomaly	-.117	-.111	-.081	-.112	-.091	-.024	-.151	-.142	-.144	-.103
Medical Termination	.027	.098	-.018	.121	-.058	-.094	.017	-.029	.052	.015
Surgical Termination	.042	.054	.096	.018	.127	.109	.013	.195*	-.106	-.035
Decision to terminate	-.060	.129	.040	.103	.015	.001	.064	.000	.049	.126
Decision in method	-.129	-.129	-.118	-.104	-.134	-.088	-.060	-.039	-.080	-.029
Diagnosis	-.070	-.027	-.136	.014	-.178*	-.195*	-.069	-.229**	.043	-.013
Decision to terminate	-.010	.041	-.001	.128	-.063	-.048	.019	-.144	.126	.046
Positive Behavioural change	-.176*	-.046	-.175*	-.036	-.266**	-.160*	-.082	-.211*	.016	-.035
Emotional responsiveness	-.143	-.052	-.189*	-.069	-.258**	-.179**	-.096	-.160*	-.048	-.048
Quality of time shared	-.229**	-.124	-.253**	-.103	-.323***	-.254*	-.150	-.269**	-.048	-.090
Time Since Termination	-.386**	-.394**	-.384**	-.488**	-.338**	-.255**	-.390**	-.160	-.452**	-.387**
Coping through Religion	.065	.069	.082	.041	.020	.167	.151	.154	.095	.157*
Self-Distraction	.119	.167*	.156*	.188*	.117	.134	.217*	.211*	.217*	.128

Active Coping	-.204*	-.033	-.169*	-.083	-.175*	-.201*	-.083	-.079	-.077	-.059
Denial	.341***	.346***	.340***	.382***	.276***	.296**	.404***	.285***	.349***	.430***
Substance use	.100	.028	.086	.012	.139	.075	.170*	.169*	.131*	.146
Use of emotional support	-.146	-.019	-.014	.070	-.037	-.059	-.018	-.090	.010	.032
Use of instrumental support	-.024	.115	.013	.069	.009	-.037	.057	-.073	.087	.136
Behavioural Disengagement	.514***	.450***	.450***	.396***	.410***	.442***	.426***	.300***	.355***	.473***
Venting	.161*	.352***	.302***	.315***	.247**	.282***	.169*	-.094	.240**	.289**
Positive Reframing	-.086	.014	-.148	-.122	-.153	-.133	.045	-.009	.050	.079
Planning	.073	.223**	.100	.159*	.075	.052	.200*	.083	.212*	.224**
Humour	.142	.094	.048	-.003	.052	.078	.070	-.002	.044	.156*
Acceptance	-.283***	-.179*	-.332***	-.251**	-.317***	-.347***	-.210*	-.217**	-.153	-.188*
Self- blame	.387***	.415***	.575***	.528***	.477***	.596***	.444	.313***	.413***	.434***

[4]* p <0.05 **p < 0.01 ***p < 0.001

*Separate Social Support scores in the areas of diagnosis, decision to terminate, positive behavioural change, emotional responsiveness and quality of time shared were entered in to stage two of the model.

[4] Due to the no. of correlations, the reader should be cautious not to focus on significance values (due to Type I error-rate). Of more relevance here (essentially pre-cursor analyses for the main regression analysis) are the effect-sizes (i.e., correlation coefficients).

Table 23 Summary of Hierarchical Regression Analysis for factors predicting Depression as measured by the HADS-D *(N=122).*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*β*
Congenital Abnormality	0.35	1.82	0.03	0.32	1.69	0.03	0.35	1.57	0.03
Chromosomal Anomaly	-0.83	1.65	-0.09	-1.46	1.53	-0.16	-0.73	1.48	-0.08
Nervous System Anomaly	-1.76	1.79	-0.17	-1.34	1.64	-0.13	-1.62	1.54	-0.16
Medical Termination	0.32	1.04	0.03	-1.49	0.97	-0.16	-0.34	0.90	-0.04
Surgical Termination	1.11	1.61	0.08	-0.26	1.48	-0.02	-1.63	1.40	-0.11
Decision to terminate	-0.42	0.55	-0.08	-0.54	0.50	-0.10	-0.66	0.47	-0.12
Decision in method	-0.46	0.32	-0.14	-0.38	0.30	-0.12	-0.19	0.27	-0.06
[a]Diagnosis				0.03	1.48	0.00	1.38	1.36	0.12
[b]Decision to terminate				0.26	1.17	0.03	-0.06	1.03	-0.01
[c]Positive behavioural change				0.03	1.31	0.00	-0.20	1.16	-0.02
[d]Emotional responsiveness				-0.78	1.39	-0.08	0.55	1.22	0.06
[e]Quality of time shared				-3.05	1.69	-0.29	-2.94	1.53	-0.28
Time Since Termination				-1.45	0.27	-0.52****	-0.86	0.26	-0.31**
Coping through Religion							-0.04	0.23	-0.01
Self-Distraction							0.04	0.24	0.02
Active Coping							-0.21	0.30	-0.08

Denial			0.21	0.43	0.05
Substance use			0.42	0.28	0.12
Use of emotional support			-0.47	0.27	-0.19
Use of instrumental support			0.15	0.27	0.06
Behavioural Disengagement			1.32	0.38	0.32***
Venting			0.02	0.27	0.01
Positive Reframing			-0.15	0.24	-0.06
Planning			0.58	0.28	0.23*
Humour			0.09	0.35	0.02
Acceptance			-0.45	0.33	-0.15
Self- blame			0.52	0.21	0.21*
***R*²**	**0.049**	**0.308******		**0.583*****	
***F* for change in *R*²**	**0.774**	**3.430******		**4.458******	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 24 Summary of Hierarchical Regression Analysis for factors predicting Anxiety as measured by the HADS-A *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	0.62	1.95	0.05	0.85	1.91	0.07	1.15	1.80	0.09
Chromosomal Anomaly	-0.20	1.76	-0.02	-0.51	1.73	-0.05	0.13	1.70	0.01
Nervous System Anomaly	-0.60	1.91	-0.05	-0.03	1.86	0.00	-0.04	1.77	0.00
Medical Termination	1.22	1.11	0.12	-0.39	1.09	-0.04	0.51	1.04	0.05
Surgical Termination	2.28	1.71	0.14	1.26	1.67	0.08	-0.30	1.61	-0.02
Decision to terminate	0.79	0.59	0.14	0.57	0.57	0.10	0.39	0.54	0.07
Decision in method	-0.61	0.35	-0.17	-0.55	0.33	-0.16	-0.38	0.31	-0.11
[a]Diagnosis				-0.11	1.67	-0.01	0.94	1.56	0.08
[b]Decision to terminate				-0.17	1.32	-0.02	-0.50	1.18	-0.05
[c]Positive behavioural change				0.88	1.48	0.09	0.54	1.33	0.06
[d]Emotional responsiveness				-0.80	1.56	-0.08	0.33	1.41	0.03
[e]Quality of time shared				-2.46	1.91	-0.22	-2.15	1.76	-0.19
Time Since Termination				-1.37	0.31	-0.45****	-0.80	0.30	-0.27**
Coping through Religion							-0.05	0.26	-0.02
Self-Distraction							0.18	0.28	0.06
Active Coping							-0.02	0.34	-0.01

Denial			0.07	0.50	0.01
Substance use			-0.03	0.32	-0.01
Use of emotional support			-0.54	0.31	-0.20
Use of instrumental support			0.14	0.31	0.05
Behavioural Disengagement			1.06	0.43	0.24*
Venting			0.58	0.31	0.19
Positive Reframing			0.01	0.27	0.00
Planning			0.59	0.32	0.22
Humour			0.16	0.40	0.04
Acceptance			-0.63	0.38	-0.19
Self- blame			0.57	0.24	0.22*
R^2	**0.068**	**0.242**		**0.528**	
***F* for change in R^2**	**1.109**	**2.455**		**3.558**	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 25 Summary of Hierarchical Regression Analysis for factors predicting Grief as measured by the PGS-33 *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	1.28	9.04	0.02	1.26	8.15	0.02	4.40	6.83	0.07
Chromosomal Anomaly	-2.54	8.19	-0.06	-6.02	7.38	-0.13	-0.67	6.43	-0.01
Nervous System Anomaly	-4.52	8.88	-0.09	-2.57	7.93	-0.05	-3.95	6.72	-0.08
Medical Termination	0.27	5.14	0.01	-9.51	4.67	-0.20*	-7.21	3.93	-0.15
Surgical Termination	9.39	7.96	0.13	1.02	7.12	0.01	-10.75	6.10	-0.15
Decision to terminate	1.33	2.72	0.05	0.75	2.43	0.03	1.12	2.05	0.04
Decision in method	-2.62	1.61	-0.16	-2.07	1.42	-0.13	-0.34	1.18	-0.02
[a]Diagnosis				-7.09	7.13	-0.13	2.15	5.93	0.04
[b]Decision to terminate				5.64	5.64	0.12	0.97	4.49	0.02
[c]Positive behavioural change				2.13	6.33	0.05	1.53	5.03	0.03
[d]Emotional responsiveness				-8.35	6.68	-0.18	-4.37	5.33	-0.09
[e]Quality of time shared				-14.20	8.16	-0.27	-10.69	6.66	-0.20
Time Since Temrination				-7.37	1.33	-0.53****	-4.66	1.15	-0.34****
Coping through Religion							0.54	1.00	0.04
Self-Distraction							0.72	1.06	0.05
Active Coping							-1.17	1.30	-0.09
Denial							-0.30	1.88	-0.01

Substance use			0.32	1.20	0.02
Use of emotional support			0.12	1.17	0.01
Use of instrumental support			-0.90	1.17	-0.07
Behavioural Disengagement			3.50	1.64	0.17*
Venting			1.83	1.16	0.13
Positive Reframing			-1.30	1.02	-0.10
Planning			2.35	1.20	0.19
Humour			-0.62	1.51	-0.03
Acceptance			-3.51	1.44	-0.23*
Self- blame			4.96	0.90	0.41****
***R*²**	**0.042**	**0.341**		**0.677**	
***F* for change in *R*²**	**0.662**	**3.985******		**6.664********	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 26 Summary of Hierarchical Regression Analysis for factors predicting Active Grief as measured by this subscale of the PGS-33

	Model 1			Model 2			Model 3		
Variable	*B*	SE	*β*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	-0.50	2.90	-0.03	-0.90	2.64	-0.05	-0.47	2.26	-0.02
Chromosomal Anomaly	-2.22	2.62	-0.15	-3.33	2.39	-0.22	-1.56	2.13	-0.10
Nervous System Anomaly	-2.67	2.85	-0.16	-2.27	2.57	-0.14	-2.54	2.23	-0.15
Medical Termination	2.03	1.65	0.13	-0.90	1.52	-0.06	-0.28	1.30	-0.02
Surgical Termination	2.36	2.55	0.10	0.63	2.31	0.03	-3.67	2.02	-0.16
Decision to terminate	0.74	0.87	0.09	0.26	0.79	0.03	0.24	0.68	0.03
Decision in method	-0.70	0.51	-0.14	-0.57	0.46	-0.11	0.14	0.39	0.03
[a]Diagnosis				-0.35	2.31	-0.02	3.05	1.97	0.17
[b]Decision to terminate				1.63	1.83	0.11	0.42	1.49	0.03
[c]Positive behavioural change				1.37	2.05	0.10	1.09	1.67	0.08
[d]Emotional responsiveness				-3.60	2.17	-0.23	-2.47	1.77	-0.16
[e]Quality of time shared				-3.07	2.65	-0.18	-2.20	2.21	-0.13
Time Since Termination				-2.47	0.43	-0.55****	-1.61	0.38	-0.36****
Coping through Religion							0.02	0.33	0.01
Self-Distraction							0.06	0.35	0.01
Active Coping							-0.26	0.43	-0.06

Denial			0.84	0.62	0.11
Substance use			-0.10	0.40	-0.02
Use of emotional support			0.23	0.39	0.06
Use of instrumental support			-0.62	0.39	-0.16
Behavioural Disengagement			0.92	0.54	0.14
Venting			0.65	0.38	0.14
Positive Reframing			-0.61	0.34	-0.15
Planning			0.85	0.40	0.22*
Humour			-0.54	0.50	-0.08
Acceptance			-0.84	0.48	-0.17
Self- blame			1.51	0.30	0.39****
R^2	**0.059**	**0.338**		**0.660**	
***F* for change in R^2**	**0.951**	**3.922******		**6.191******	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 27 Summary of Hierarchical Regression Analysis for factors predicting Difficulty Coping as measured by this subscale of the PGS-33

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	1.42	3.55	0.06	0.99	3.16	0.04	2.12	3.07	0.09
Chromosomal Anomaly	0.75	3.21	0.04	-1.11	2.86	-0.06	0.47	2.89	0.03
Nervous System Anomaly	-0.81	3.48	-0.04	-0.37	3.08	-0.02	-1.16	3.02	-0.06
Medical Termination	-0.61	2.02	-0.03	-4.37	1.81	-0.24*	-3.74	1.76	-0.20*
Surgical Termination	4.22	3.12	0.15	0.62	2.76	0.02	-3.53	2.74	-0.12
Decision to terminate	0.40	1.07	0.04	0.45	0.94	0.04	0.32	0.92	0.03
Decision in method	-1.15	0.63	-0.18	-0.98	0.55	-0.15	-0.45	0.53	-0.07
[a]Diagnosis				-2.20	2.77	-0.10	0.47	2.66	0.02
[b]Decision to terminate				1.87	2.19	0.10	0.42	2.02	0.02
[c]Positive behavioural change				-0.76	2.46	-0.04	-0.92	2.26	-0.05
[d]Emotional responsiveness				-3.08	2.59	-0.16	-1.27	2.39	-0.07
[e]Quality of time shared				-5.62	3.17	-0.27	-4.86	2.99	-0.24
Time Since Termination				-2.76	0.52	-0.50****	-1.83	0.51	-0.33***
Coping through Religion							-0.11	0.45	-0.02
Self-Distraction							0.23	0.48	0.04
Active Coping							-0.27	0.58	-0.05
Denial							-0.29	0.84	-0.03

Substance use			0.53	0.54	0.08
Use of emotional support			-0.13	0.53	-0.03
Use of instrumental support			0.06	0.52	0.01
Behavioural Disengagement			1.31	0.73	0.16
Venting			0.46	0.52	0.08
Positive Reframing			-0.32	0.46	-0.07
Planning			0.79	0.54	0.16
Humour			0.00	0.68	0.00
Acceptance			-1.38	0.65	-0.23*
Self- blame			1.49	0.40	0.31****
***R*^{2}**	**0.054**	**0.362**		**0.581**	
***F* for change in *R*^{2}**	**0.861**	**4.359******		**4.415********	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 28 Summary of Hierarchical Regression Analysis for factors predicting Despair as measured by this subscale of the PGS-33

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*β*
Congenital Abnormality	0.36	3.30	0.02	1.17	3.14	0.05	2.74	2.62	0.13
Chromosomal Anomaly	-1.08	2.98	-0.06	-1.59	2.84	-0.10	0.42	2.47	0.02
Nervous System Anomaly	-1.05	3.24	-0.06	0.08	3.05	0.00	-0.25	2.58	-0.01
Medical Termination	-1.15	1.87	-0.07	-4.25	1.80	-0.25*	-3.20	1.51	-0.19*
Surgical Termination	2.81	2.90	0.11	-0.23	2.74	-0.01	-3.55	2.34	-0.14
Decision to terminate	0.19	0.99	0.02	0.04	0.93	0.00	0.56	0.79	0.06
Decision in method	-0.77	0.58	-0.13	-0.52	0.55	-0.09	-0.03	0.45	0.00
[a]Diagnosis				-4.53	2.75	-0.22	-1.37	2.27	-0.07
[b]Decision to terminate				2.15	2.17	0.13	0.13	1.72	0.01
[c]Positive behavioural change				1.52	2.44	0.09	1.37	1.93	0.08
[d]Emotional responsiveness				-1.67	2.57	-0.10	-0.62	2.04	-0.04
[e]Quality of time shared				-5.52	3.14	-0.29	-3.62	2.55	-0.19
Time Since Termination				-2.14	0.51	-0.42****	-1.22	0.44	-0.24****
Coping through Religion							0.63	0.39	0.13
Self-Distraction							0.43	0.41	0.09
Active Coping							-0.64	0.50	-0.13
Denial							-0.85	0.72	-0.10

Substance use			-0.11	0.46	-0.02
Use of emotional support			0.01	0.45	0.00
Use of instrumental support			-0.35	0.45	-0.08
Behavioural Disengagement			1.28	0.63	0.17*
Venting			0.72	0.44	0.14
Positive Reframing			-0.37	0.39	-0.08
Planning			0.71	0.46	0.16
Humour			-0.07	0.58	-0.01
Acceptance			-1.29	0.55	-0.24*
Self- blame			1.95	0.35	0.45****
R^2	**0.34**	**0.259**		**0.639**	
***F* for change in R^2**	**0.534**	**2.682*** **		**5.630**** **	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 29 Summary of Hierarchical Regression Analysis for factors predicting symptoms of post-traumatic stress as measured by the IES

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*β*
Congenital Abnormality	0.21	6.95	0.00	1.21	6.64	0.03	1.29	6.03	0.03
Chromosomal Anomaly	-0.76	6.29	-0.02	-1.98	6.01	-0.06	0.23	5.67	0.01
Nervous System Anomaly	-6.16	6.82	-0.16	-3.88	6.46	-0.10	-6.21	5.93	-0.16
Medical Termination	-0.50	3.95	-0.01	-7.07	3.80	-0.20	-4.52	3.47	-0.13
Surgical Termination	0.63	6.12	0.01	-4.22	5.80	-0.08	-12.08	5.38	-0.22*
Decision to terminate	0.91	2.09	0.04	0.13	1.98	0.01	-0.21	1.81	-0.01
Decision in method	-0.98	1.23	-0.08	-0.69	1.16	-0.06	0.30	1.04	0.02
[a]Diagnosis				-4.17	5.81	-0.10	2.49	5.24	0.06
[b]Decision to terminate				1.63	4.59	0.05	0.29	3.96	0.01
[c]Positive behavioural change				3.27	5.16	0.10	1.25	4.44	0.04
[d]Emotional responsiveness				-4.32	5.44	-0.12	-0.81	4.70	-0.02
[e]Quality of time shared				-8.62	6.64	-0.22	-8.04	5.88	-0.20
Time Since Termination				-5.30	1.08	-0.50****	-2.87	1.01	-0.27***
Coping through Religion							0.25	0.89	0.02
Self-Distraction							0.35	0.93	0.03
Active Coping							-0.75	1.14	-0.07
Denial							2.96	1.66	0.17

Substance use			2.36	1.06	0.18*
Use of emotional support			-0.61	1.03	-0.06
Use of instrumental support			0.00	1.03	0.00
Behavioural Disengagement			3.19	1.44	0.20*
Venting			-0.87	1.02	-0.08
Positive Reframing			0.26	0.90	0.03
Planning			2.52	1.06	0.27*
Humour			-1.13	1.34	-0.07
Acceptance			-1.89	1.27	-0.16
Self- blame			2.94	0.79	0.32****
***R*^{2}**	**0.030**	**0.251******		**0.528********	
***F* for change in *R*^{2}**	**4.67**	**2.575*****		**4.183********	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 30 Summary of Hierarchical Regression Analysis for factors predicting symptoms of Avoidance as measured by that subscale of the IES*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*B*	*B*	SE	*B*
Congenital Abnormality	-0.14	0.31	-0.07	-0.07	0.32	-0.03	-0.01	0.32	0.00
Chromosomal Anomaly	-0.18	0.28	-0.11	-0.21	0.29	-0.13	-0.16	0.30	-0.10
Nervous System Anomaly	-0.37	0.31	-0.21	-0.29	0.31	-0.16	-0.35	0.31	-0.20
Medical Termination	0.07	0.18	0.04	-0.12	0.18	-0.07	0.03	0.18	0.02
Surgical Termination	0.55	0.28	0.22	0.33	0.28	0.13	0.28	0.28	0.11
Decision to terminate	-0.02	0.09	-0.02	0.00	0.10	0.00	0.03	0.10	0.03
Decision in method	-0.05	0.06	-0.08	-0.03	0.06	-0.06	-0.03	0.05	-0.05
[a]Diagnosis				-0.22	0.28	-0.11	-0.02	0.28	-0.01
[b]Decision to terminate				-0.01	0.22	-0.01	-0.07	0.21	-0.04
[c]Positive behavioural change				0.01	0.25	0.01	-0.01	0.23	0.00
[d]Emotional responsiveness				0.05	0.26	0.03	0.08	0.25	0.05
[e]Quality of time shared				-0.49	0.32	-0.27	-0.50	0.31	-0.27
Time Since Termination				-0.12	0.05	-0.25*	-0.04	0.05	-0.08
Coping through Religion							0.06	0.05	0.12
Self-Distraction							0.04	0.05	0.09
Active Coping							0.02	0.06	0.04
Denial							0.08	0.09	0.11

Substance use			0.11	0.06	0.18
Use of emotional support			-0.01	0.05	-0.02
Use of instrumental support			0.00	0.05	0.00
Behavioural Disengagement			0.18	0.08	0.25*
Venting			-0.18	0.05	-0.36***
Positive Reframing			0.03	0.05	0.07
Planning			0.05	0.06	0.12
Humour			-0.07	0.07	-0.10
Acceptance			-0.05	0.07	-0.09
Self- blame			0.10	0.04	0.23*
R^2	**0.066**	**0.175**		**0.437**	
***F* for change in R^2**	**0.1063**	**1.633**		**2.470*** **	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 31 Summary of Hierarchical Regression Analysis for factors predicting symptoms of Intrusions as measured by that subscale of the IES*

	Model 1			Model 2			Model 3		
Variable	*B*	SE	*β*	*B*	SE	*B*	*B*	SE	*β*
Congenital Abnormality	0.08	0.39	0.03	0.09	0.36	0.04	0.03	0.33	0.01
Chromosomal Anomaly	0.12	0.35	0.06	0.05	0.33	0.02	0.17	0.31	0.09
Nervous System Anomaly	-0.25	0.38	-0.11	-0.15	.035	-0.07	-0.29	0.33	-0.13
Medical Termination	-0.08	0.22	-0.04	-0.46	0.21	-0.23*	-0.42	0.19	-0.21*
Surgical Termination	-0.38	0.34	-0.12	-0.59	0.32	-0.19	-1.14	0.30	-0.37****
Decision to terminate	0.04	0.12	0.03	-0.04	0.11	-0.04	-0.09	0.10	-0.08
Decision in method	-0.05	0.07	-0.07	-0.03	0.06	-0.05	0.04	0.06	0.05
[a]Diagnosis				-0.19	0.32	-0.08	0.14	0.29	0.06
[b]Decision to terminate				0.20	0.25	0.10	0.16	0.22	0.08
[c]Positive behavioural change				0.29	0.28	0.15	0.16	0.25	0.08
[d]Emotional responsiveness				-0.44	0.30	-0.22	-0.23	0.26	-0.11
[e]Quality of time shared				-0.29	0.36	-0.13	-0.17	0.32	-0.08
Time Since Termination				-0.33	0.06	-0.55****	-0.21	0.06	-0.36****
Coping through Religion							-0.03	0.05	-0.05
Self-Distraction							0.03	0.05	0.05
Active Coping							-0.10	0.06	-0.17

Denial			0.15	0.09	0.16
Substance use			0.11	0.06	0.14
Use of emotional support			-0.06	0.06	-0.12
Use of instrumental support			-0.02	0.06	-0.03
Behavioural Disengagement			0.08	0.08	0.09
Venting			0.05	0.06	0.09
Positive Reframing			0.00	0.05	-0.01
Planning			0.16	0.06	0.30***
Humour			-0.09	0.07	-0.10
Acceptance			-0.07	0.07	-0.11
Self- blame			0.17	0.04	0.32****
R^2	**0.42**	**0.301**		**0.583**	
***F* for change in R^2**	**0.663**	**3.308******		**4.462******	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

Table 32 Summary of Hierarchical Regression Analysis for factors predicting symptoms of Hyperarousal as measured by that subscale of the IES*

	Model 1			Model 2			Model 3		
Variable	*B*	SE	*β*	*B*	SE	*B*	*B*	SE	*β*
Congenital Abnormality	0.12	0.38	0.05	0.17	0.37	0.07	0.18	0.32	0.07
Chromosomal Anomaly	-0.05	0.34	-0.02	-0.11	0.33	-0.06	0.02	0.30	0.01
Nervous System Anomaly	-0.19	0.37	-0.09	-0.06	0.36	-0.03	-0.17	0.32	-0.08
Medical Termination	-0.06	0.22	-0.03	-0.40	0.21	-0.20	-0.24	0.19	-0.12
Surgical Termination	-0.12	0.34	-0.04	-0.36	0.32	-0.12	-0.87	0.29	-0.29**
Relative autonomy* in decision to terminate	0.13	0.11	0.11	0.08	0.11	0.08	0.04	0.10	0.04
Relative autonomy* in method of termination	-0.04	0.07	-0.05	-0.03	0.06	-0.04	0.04	0.06	0.06
[a]Diagnosis				-0.15	0.32	-0.07	0.25	0.28	0.11
[b]Decision to terminate				0.02	0.26	0.01	-0.07	0.21	-0.04
[c]Positive behavioural change				0.15	0.29	0.08	0.01	0.24	0.00
[d]Emotional responsiveness				-0.20	0.30	-0.10	0.06	0.25	0.03
[e]Quality of time shared				-0.39	0.37	-0.18	-0.44	0.32	-0.20
Time Since Termination				-0.28	0.06	-0.49****	-0.14	0.05	-0.24*
Coping through Religion							0.01	0.05	0.01
Self-Distraction							-0.04	0.05	-0.06
Active Coping							-0.02	0.06	-0.03

Denial			0.18	0.09	0.19*
Substance use			0.11	0.06	0.14
Use of emotional support			-0.01	0.06	-0.01
Use of instrumental support			0.02	0.06	0.05
Behavioural Disengagement			0.20	0.08	0.23*
Venting			0.02	0.05	0.04
Positive Reframing			0.01	0.05	0.01
Planning			0.14	0.06	0.27*
Humour			0.02	0.07	0.03
Acceptance			-0.15	0.07	-0.20*
Self- blame			0.14	0.04	.27*
R^2	**0.030**	**0.231**		**0.586**	
***F* for change in R^2**	**0.476**	**2.311****		**4.505********	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

**Satisfaction with social support entered as 5 distinct predictor variables according to the following areas; adaptation[a], partnership[b], growth[c], affection[d] and resolve[e]*

14.0 Extended Discussion

14.1 Clinical implications

The extended discussion will focus on the clinical implications associated with the key findings of the current study. It is the first study to make the link between coping styles and psychological outcome in women who have terminated a pregnancy for fetal abnormality. It contributes to our understanding in this area by highlighting how coping styles that are high in self-blame, denial, and behavioural disengagement are significant predictors of increased psychological distress. In contrast coping based on acceptance appeared to protect the women. Clinical Psychology possesses a number of evidence based and empirically supported interventions that are relevant to difficulties associated with these processes.

14.1.2 Compassion Focussed Therapy (CFT) & Self Blame

Self-blame is associated with high levels of shame. It is linked with an increased vulnerability to psychological problems and is known to affect expressions of symptoms, abilities to disclose painful information, numerous forms of avoidance (e.g., behavioural disengagement and denial) and creates a barrier to seeking help. According to Gilbert and Procter (2006) shame comprises of external and internal forces. External shame is concerned with the thoughts and feelings of how one is viewed in the minds of others. It is marked by the assumption that others will look upon the self negatively and that people will inevitably dislike, reject and even attack aspects of the self that are viewed badly. Internal shame emerges through self-devaluation and self-blame where an individual is sensitised to their own perceived inadequacies and wrongdoings.

CFT was developed for people with high shame and self-criticism which is thought to prevent people from progressing as well with standard CBT (Rector, Bagby, Segal, Joffe and Levitt, 2000). It proposes a network of three interacting affect-regulation systems in the brain (resource-focused, affiliative-focused and threat-focused; Gilbert, 2005). The resource-focused system helps us achieve our wants/needs, the threat system allows us to protect ourselves, and the affiliative system engenders evolutionary safeness and security. Closely resembling theories of attachment, it suggests that if a child is loved and regularly soothed their affiliative system will thrive, whereas if they are threatened or unsafe, their threat system is stimulated. If this occurs too often, people may find it difficult to feel secure or content (highly activated threat system) or be driven to prove themselves (highly activated resource system). Therapy aims to strengthen the affiliative system by

developing self-soothing and safeness through self-compassion. Although reducing self-directed resentment is important to reduce self-blame and shame, CFT also aims to foster within the person their ability to generate feelings of self-assurance, compassion, and self-soothing. This can be especially helpful for people who understand the logic of traditional CBT but due to their own high levels of self-criticism, shame and blame rarely feel any better in themselves (Gilbert & Proctor, 2006).

While CFT refers to the process, Compassionate Mind Training (CMT) refers to the exercises and practices in CFT, but can also be used alone for anyone wanting to develop their compassion. Given that the current findings in this study indicated that high levels of self-blame were indicative of worse psychological outcome, CFT and elements of CMT could help strengthen a woman's affiliative system after a TOPFA. There's a large focus on imagery, such as exercises imagining compassion flowing out from the patient to others, along with flowing inwards to themselves (from others and from the self). Such interventions could help women in this context reduce levels of self-blame by helping them to experience feelings of kindness, self-compassion and warmth and overcome their fear of being judged by others (Lafarge, Mitchell & Fox, 2013).

14.1.3 Behavioural Activation & Avoidant type coping

Behavioural activation was developed from early behavioural models of depression. These models proposed that a reduction in response-contingent reinforcement for non-depressive behaviour is fundamental to the onset of depressive affect (Ferster, 1973; Lewinsohn, 1974; Lewinsohn & Graf, 1973). According to Skinner (1953), depression occurs when healthy behaviour is no longer positively reinforced by the social environment. Lewinsohn (1974) elaborated on this idea to explain how a reduction in healthy behaviour can be understood by examining the presence (or absence) of the number and range of positively reinforcing stimuli. He also highlighted the impact of punishment on a person's tendency to behave healthily. A functional analytic account postulates that sustained engagement of depressed behaviour occurs through a mixture of increased reinforcement for the depressed behaviour and a lack of reinforcement for more adaptive alternative behaviour (Ferster, 1973). According to Ferster (1973) depressed behaviour (e.g. behavioural disengagement) strengthens when environmental contingencies serve to reduce the rate of healthy behaviour within an individual's repertoire and increases their avoidance of aversive stimuli.

Hopko et al, (2003) define Behavioural Activation (BA) "...as a therapeutic process that emphasizes structured attempts at engendering increases in overt behaviours that are likely to bring the patient into contact with reinforcing environmental contingencies and produce corresponding improvements in thoughts, mood, and overall quality of life." (p700). BA has been proven effective for both individual and group interventions (Martell et al., 2001; BATD; Lejuez, Hopko, & Hopko, 2001, 2002). It focuses on the evolving transactions that occur over time between an individual and their environment and is concerned with identifying and targeting environmental triggers and ineffective coping responses that appear to both create and maintain depressed mood (Jacobson et al., 2001; Martell et al., 2001). Depressed behaviour, including behavioural disengagement and withdrawal are viewed as a coping strategy to avoid environmental contexts that comprise low levels of positive reinforcement or include overwhelming levels of aversive control. Therefore, behavioural avoidance is a key concept to the BA treatment approach.

The current findings point to the detrimental effects associated with prolonged use of behavioural disengagement and general avoidant type coping in women who have experienced a TOPFA. Women have described how the things that they once found reinforcing, e.g. spending time with friends and their families can often become aversive in the aftermath of their own loss (Lafarge, Mitchell & Fox, 2013). Although there is some evidence that women initially find avoidance helpful, they accept that it also has long term negative implications, particularly by preventing them from working through their emotions (Lafarge, Mitchell, Fox, 2013). BA uses the collaborative therapeutic relationship in order to help the patient to identify how an internal or external event (Trigger) causes a negative emotional (Response) that signals the start of a recurrent pattern of avoidance (Avoidance Pattern). It is easy to see how the life event of a TOPFA could result in women experiencing this TRAP (Hopko, et al, 2003). Furthermore, women in this context would arguably benefit from an understanding that avoidance, whilst initially helpful, rarely has long term positive consequences. With this knowledge, BA aims would aim to help the women to reengage in a range of healthy behaviours through the development of alternative more adaptive coping strategies (i.e., TRAC; trigger, response, alternative coping; Hopko et al, 2003).

Hopko et al (2003) argues that "Along with increased patient awareness and progression from a TRAP to a TRAC based philosophy, the primary therapeutic technique of BA involves teaching patients to take ACTION" (p 708), a primary focus of BA interventions being the move toward extinguishing escape and avoidance. Thus, women for whom escape and avoidant coping is apparent, could be taught to assess the function of their

behaviour in order to make an informed choice as to whether they wish to continue escaping and avoiding or instead engage in more adaptive behaviour that may improve their overall mood and ability to cope.

More recent behavioural activation approaches also incorporate a balanced acceptance–change model that is increasing in popularity in many areas of psychopathology (Hayes, Strosahl, & Wilson, 1999). Based on these ideas, activation partly involves teaching clients to plan and develop behavioural goals irrespective of their thoughts. Acceptance-change theories are particularly relevant in the context of the current results, as coping strategies high in acceptance were predictive of better outcomes and reduced psychological distress.

14.1.4 Acceptance and Commitment Therapy (ACT) & coping through Acceptance

Both ACT and Relational Frame Theory (RFT) are underpinned by complex and technical theoretical assumptions and it is beyond the scope of this account to fully address them here. Instead a brief introduction, focusing on aspects of the approach relevant to the study findings is provided. Acceptance and commitment therapy is grounded in relational frame theory (RFT). RFT is a behavioural account of language and higher cognition that is based on a philosophical approach known as Functional Contextualism. Functional Contextualism highlights the importance of predicting and influencing psychological events such as thoughts, feelings, and behaviours, by focusing on manipulable variables in the context in which these events occur (Hayes et al, 2006). It focuses on how humans learn to communicate and develop their linguistic repertoire through interactions with the environment. RFT proposes that “the core of human language and cognition is the learned and contextually controlled ability to arbitrarily relate events mutually and in combination, and to change the functions of specific events based on their relations to other” (Hayes et al, 2006 p5).

In summarising RFT, Hayes et al (2006) highlight three critical features to the approach;

1. Human cognition is a specific kind of learned behaviour.
2. Cognition alters the effects of other behavioural processes
3. Cognitive relations and cognitive functions are regulated by different contextual features of a situation

(p6)

There are a number of other ideas central to RFT, including; the idea that verbal reasoning and problem solving are governed by the same cognitive processes that can

lead to psychopathology, and therefore it is unrealistic to try to extinguish or target these processes. Secondly, although extinction is relatively successful in eliminating learned behaviour, it is unrealistic to assume that the underlying cognitive networks can too be eliminated as they are the product of historical learning. In contrast, attempts to change specific nodes within a cognitive network are in fact more likely to strengthen the associated cognitive networks and enhance the functional importance of the very nodes that we are aiming to eliminate (Hayes et al, 2006). Nevertheless, because the content and impact of cognitive networks are controlled by distinct contextual factors, it is still possible to reduce their impact when they do occur. Based upon these ideas, RFT informed interventions would not focus primarily on the changing the content of a thought, but would instead think about its function.

ACT takes its name from one of its core messages: to accept what is outside of your personal control, while committing to action that will improve your quality of life. ACT aims to support people to build a full and meaningful life, and it teaches people the skills to successfully handle the pain and stress that may jeopardises this. Interventions focus on;

1. Teaching the psychological skills necessary to cope with painful thoughts and feelings effectively and in such a way that they have significantly less impact and influence over you. This is primarily done through the development of mindfulness based skills.
2. Helping individuals to clarify what is truly important and meaningful to them. Once they are clear of their values and goals, they are then encouraged to use this knowledge to guide, inspire and motivate them to make positive life changes

Achieving a state of mindfulness, in which difficult thoughts and feelings have much less impact and influence is something that might benefit the women within this study. ACT breaks mindfulness skills down into 3 categories:

1. Diffusion: distancing from, and letting go of, unhelpful thoughts, beliefs and memories.
2. Acceptance: making room for painful feelings, urges and sensations, and allowing them to come and go without a struggle.
3. Contact with the present moment: engaging fully with your here-and-now experience, with an attitude of openness and curiosity.

The current study helped to establish how coping styles that are high in acceptance help to predict better outcomes on a number of standardised outcomes measures of psychological distress. In keeping with the ideas of ACT, this study suggests that women who undergo a TOPFA are likely to benefit from aftercare in which acceptance is taught as an alternative to experiential avoidance. Acceptance would involve the active and aware embrace of those private events (thoughts/ images) relating the event of a TOPFA without unnecessary attempts to alter their frequency or form, as doing so would potentially cause further psychological harm. Acceptance (and diffusion) in ACT is not an end in itself and the women would need to be taught that acceptance should be fostered as a means of increasing their overall values-based actions.

14.2 Conclusions & Future Directions

Each other the treatment approaches outlined above share many key assumptions with contemporary theories of bereavement, grief and psychological coping. They each represent attempts to reduce psychological distress and suffering and stress that the ways in which distress manifests and affects an individual is the outcome of a dynamic process in which it is vital to focus on function over form. The approaches considered above are able to draw upon established theories of grief and coping to help support women in this context. Furthermore, through the development of individualised psychological formulations and treatment plans, they would enable us to integrate our general theoretical understanding of these processes with a more person-centred approach, capable of reflecting the subjective qualities known to exist amongst these phenomenon's. The findings from Lafarge, Mitchell and Fox (2013), taken with the current findings, highlight the value of considering coping styles in this context. It is imperative that future research focuses on evaluating the benefits of psychologically informed interventions which teach more adaptive coping responses. Also, to account for the fact that different women may wish to access support at different times, often depending on the extent of their self-blame and shame, extra efforts must be made to ensure that they recognise that support is available and feel able to seek it when needed.

15.0 Critical Reflections

15.1 Ethics

A major consideration throughout my thesis has been in the use of appropriate language. Given the sensitive nature of this type of research a major ethical considerations lain in

the way I communicated with my participants. Namely through the language that I used to describe my study (e.g. participant information sheets, adverts etc.) and construct my survey, but also in selecting outcome measures that comprised sensitive, neutral and un-prejudiced language. Although the current research questions were best answered though a positivist epistemological approach, I was frequently influenced by the ideas of Michael White and David Epston (1990). Their development of Narrative Therapy and my understanding of their work has allowed me to think critically about my potential as main researcher, to influence the context of the study through the use of value laden narratives.

The Narrative approach shares the social constructivist premise that individuals' identities are not fixed and singular, but fluid and changeable, according to their context (Freedman & Combs, 1996). Morgan (2000) describes how language is the bedrock from which reality is constructed or 'co-created' and that it is through the social process of communication that we ascribe meaning (Bateson, 1972). With Narrative principles in mind, I was aware of the potential for the language used throughout the study to influence the way potential participants make sense of their experiences. I was conscious of the possibility that participants could be heavily influenced by the language and descriptions that might be used to set the study up, and that this could subsequently influence the 'stories' and 'narratives' that they construct about themselves and their experience of a TOPFA. According to Narrative principles, these stories are constitutive of life, they both form and reflect the ideas we have about ourselves; they influence how we think, feel, and behave, not only in current, but also novel situations (White & Epston, 1990) and for these reasons it was particularly important to avoid the use of language that could serve to prejudice, pathologise and limit my participants responses. For example through my many revisions of the survey and the piloting of my participant materials, I refrained from describing the TOPFA as a 'Traumatic' or 'painful' experience instead using the more inclusive use of the term 'life event'. Although my primary role as an aspiring Clinical Psychologist includes a tendency to use empathic descriptive language, often borne out of an attempt to make my client feel understood, in this instance, and in my role as researcher, this would have been entirely unhelpful. By using assumptive language in order to communicate with potential participants, I would have contributed to the construction of a problem focussed narrative which would likely have been unhelpful and could become the frame through which the women participating in my study make meaning about for example the extent of their self-worth.

A fundamental assumption of narrative therapy which was highly influential throughout is the idea that problems are located in contexts and in relationships, not in people. For these reasons it was vital that potential participants were not met with a problematic

research context which appeared to communicate the assumption that the women would be and should be feeling a certain way. Despite my best attempts, I have a number of instances where I felt compromised and occasionally lost along the way. The first instance was in developing the research protocol and in beginning to formulate my research questions. It was at this time that I became aware of personal bias stemming from my assumption that a TOPFA would primarily be a negative life event characterised by distress and psychological pain. Although within the literature there are numerous examples that this is the case, a critical reflection of the current study and others before it, is the failure to incorporate a measure of psychological growth, instead focussing on the negative consequences. Other researchers have described the positive outcomes of grief, even claiming that "the existential experience" of loss can introduce the bereft to an experience of existential growth as they rebuild their life incorporating their loss and suffering in order to develop a new sense of purpose (Hogan & Desantis, 1992).

A second example came when choosing outcome measures, particularly suitable ones. A major difficulty I encountered was again related to the language used throughout many of the leading standardised scales. For example measures designed specifically for use with post-partum samples such as the Edinburgh Post Natal Depression Scale (EPDS) were considered. Such scales claim to reduce the probability of encountering 'false positives' through the use of self-report questionnaires not designed specifically for use during pregnancy and in the puerperium (Cox, Holden, Sagovsky, 1987). However, the advantages of using the EPDS which includes their careful amendment to items on somatic symptoms and sleep to account for the post-partum changes expected as a result of a new baby were not suitable for many women within the target sample who had made the choice to terminate their pregnancies. Given this, and the language bias towards women with a living child, the advantages of using this measure over the HADS were not enough to support its use. Even my final protocol included standardized outcome measures which comprised of terminology that were not ideal. The PGS-33 includes items that refer to the 'baby'. It could be argued that this wording is neither politically or ethically sensitive and has the potential to exclude and perhaps even offend potential participants that might not think of the fetus as a baby. Nevertheless, examination of the completions rates at each point of the survey did not indicate that any women opted out at this point and therefore one might conclude that this was not a major cause for concern in the current sample. As my protocol developed, I learnt to limit my use of assumptive language in the hope that this would minimise any negative consequences. Nevertheless, I am able to recognise that even my final protocol included some evidence of assumptive language and included an element of compromise which might have failed to capture how

some women conceptualised this life event. Nevertheless, recent research indicates that most women in this context prefer more compassionate humane descriptions of this event in favour of the de-personalised medical language that is often used (Lafarge, Mitchell and Fox, 2013).

Although I have alluded to the fact that my final protocol was not completely free of assumptive language, it is with thanks to the formative feedback from my markers that I began to fully appreciate and reflect critically on my use of language. The process of continual feedback without doubt helped improve my study and enabled me to gain ethical approval without any difficulties.

15.2 Underlying Epistemology and design

Given my continued appreciation of the power and influence of language, I have critically reflected on the appropriateness of the epistemological approach used. It could be argued that this study might have been more complete had it employed a mixed methods (Tashakkori & Teddlie, 2003) design. It could be argued that neither quantitative nor qualitative methods are alone sufficient to capture the trends and details of the coping responses used by women following a TOPFA. As such, the current study could have included an additional aim centred on the personal usefulness of dominant coping strategies in this context. The rationale for mixing is that when used together, quantitative and qualitative methods complement each other and allow for more complete analysis (Green, Caracelli, & Graham, 1989, Tashakkori & Teddlie, 1998; Creswell, 2002). By collecting, analysing and "mixing" both quantitative and qualitative data at some point of the research process I might have been better positioned to comment on the personal meaning and perceived usefulness of different coping responses at the individual level. The current study is limited in that it cannot propose to understand what different responses mean to different women. Although in the current study, certain coping strategies (acceptance) appear more adaptive than others (denial, self-blame, behavioural-disengagement) it is difficult to ignore that there is a subjective quality to this distinction (Carver, 1997). Furthermore, the Dual-Process Model of coping with bereavement (Stroebe & Schut, 1999) described earlier, reminds us of the dynamic processes involved in coping with a loss, in which individuals often oscillate between loss and restoration- orientated coping with one or the other proving more or less helpful at a particular time. For example it might be more helpful for an individual to resort to loss-orientated coping at times of remembrance i.e. the anniversary of the death or birthdays with the expectation that movement towards restoration-orientation will ensue. Clearly the use of a solely quantitative approach has some limitations, and whilst I can reflect upon

these, I too recognise the difficulties associated with employing a mixed methods approach; particularly the point made by my formative markers, who were concerned that this was an overly ambitious plan within the time constraints of completing a Doctorate in Clinical Psychology.

A significant limitation to this study is through its failure to incorporate a measure of premorbid psychological functioning. Korenromp et al (2007) used The Generalised Self Efficacy Scale (SES; Schwarzer, 1993) a 10-item measure in a 4-point response format, with a possible total score ranging from 10-40.This instrument assesses self-confidence as a personality characteristic, with a high score reflecting that an individual believes that he or she can cope with difficult demands. Furthermore, Kersting et al (2009) administered The State-Trait Anxiety Inventory (STAI; Speilberger & Gorsuch, 1983). Both scales provide a way of controlling for stable personality characteristics which could confound an individual's scores on the outcome measures. It would also have been helpful to have considered the impact of personality characteristics in terms of their relationship to coping responses. As with previous studies, the current study did not control for changes to participants circumstances as a result of other life events which might have occurred since the TOPFA. It is possible that the participants also experienced other difficulties (i.e. were made redundant from work or were involved in an accident) which could have influenced how they scored themselves on the outcome measures and therefore acted as a confounding variable. Future studies could control for the eventuality of other life events in order to strengthen their methodology.

Finally, Korenromp et al (2009) included a direct measure of regret over the decision to terminate. In the current study this was deemed to be too assumptive and therefore was not included to the already long protocol. Nevertheless it is worth highlighting that there is some value in gathering this type of information but it is arguably better given our earlier considerations to reframe the question to reflect satisfaction over the decision to terminate.

15.3 Personal Reflections

The personal reflections below are based upon entries I made to a reflective diary kept throughout the research process owing to the emotive subject area.

Having an infant at the time of embarking upon clinical training was always going to be a challenge, I was warned as much, and although I acknowledged this cognitively, I suspect

I never fully understood the emotional impact that having a small child would have upon me as I faced many upcoming challenges.

One challenge that I anticipated was the challenge of research, an area that I felt I had limited experience of. Despite having completed a research project at undergraduate and Master's levels, relative to my clinical experience, I certainly felt like my research skills were less well honed. Advice from previous trainees was to design a study that involved a research topic that really sparked your interest; this made sense, especially given the length of time and the many intimate nights that I would spend in its company. In deciding on a topic I thought hard about my broad areas of interest, Neuropsychology, Forensic, Learning Disabilities....there was so much! At the time my closest friend and sister, who were both pregnant were each undergoing antenatal screening tests and had responded in very different ways to the stressors associated with this process. Despite receiving a high risk result following a blood test for the Down's syndrome screening, my sister coped well with the news and employed a number of helpful coping strategies in order to make informed decisions about her own, her babies and her families' future. In contrast, my friend who had had a physically healthy pregnancy really struggled with many aspects of her antenatal care and felt anxious and uneasy throughout. Despite no evidence, she expected the worst and experienced intrusive thoughts related to her unborn baby's health. I recall reflecting on my own experience of being pregnant and of the many decisions related to the screening process. I recall it being a difficult time, characterised by some anxieties and many what if's? But I felt I coped relatively well and certainly escaped many of the difficulties encountered by my friend. I found myself hypothesising why this might be, my friend has always been a worrier - it's her nature and this pregnancy being her first was taking her into unknown waters. My sister already had two children, was a quiet methodical thinker owing to her job as a teacher; she seemed to take her current pregnancy in her stride. Perhaps her experience of already having children helped, but I acknowledged that she generally had a more active instrumental coping style than my friend.

Despite all of these ideas running through my mind, the truth was I was not sure why my friend was more vulnerable and why my sister coped so well. I could think of a few psychological and contextual differences, but I was interested to learn more and that is what led me to this broad topic area.

Right from the offset I was encouraged to think about my own biases and views in relation to the topic area and as a parent. Why had I formulated my questions as I had? I have always felt strongly that the decisions and dilemmas associated with antenatal screening

and diagnosis are very personal and individual. I do not feel strongly regarding the choices that people should make or whether any are more or less acceptable than others. However, during the development of my proposal I recognised that I was biased in my perception that each termination would be perceived as a 'loss', I learnt that my initial design included language that assumed that the women experiencing the TOPFA would all identify themselves as 'mothers' and that they would inevitably and predominantly be affected in a negative way. I left little consideration for positive impact and growth and ran the risk of excluding individuals who challenged my preconceptions, making it difficult for them to express positive impact without the fear of shattering expectations or appearing unusual in their experience. If I were to complete my research again I would unquestionably include a measure of growth.

As the study progressed I recall being overwhelmed at times with the amount of ethical considerations inherent in this area of study. I owe thanks to Helen Statham and Jane Fisher for their input and guidance as they helped to shape the protocol and assured me that it was a worthwhile and doable project.

During the data collection phase there are a number of instances where I recall reviewing the progress of incoming data late in the evening. I found this extremely difficult owing to the emotive content and nature of the work. I remember many evenings where I had laid awake thinking about my study, for these reasons my research supervisor and I discussed the benefits of shifting the times when I would check my work. These practical changes were really helpful and prevented me from becoming too immersed in the analysis at times when it was difficult to switch-off.

As I reflect on the findings of this study I am proud that I managed to pursue research in this area, despite many challenges along the way. Although I am aware of the studies limitations, I am pleased that the results have helped to highlight the value of studying the psychology of coping in this context. Finally, I recognise that my own ability to cope with the demands of this project have been informed by my work; I have approached the project systematically, I have been very mindful of personal attempts to avoid difficult aspects of the project (i.e. recruitment and analysis) and was fortunate to have the support of a great research tutor who encouraged me to keep going. An area that I may need to improve in further still is in my ability to accept that I am not currently always able to spend as much time with my son as I would ideally like. I would benefit from being kinder to myself in this regard and this is something that I am working on...

16.0 Appendices

Appendix 1 – Letter of Ethical Approval

UNIVERSITY OF
LINCOLN

15-03-2013

Dear Zoe Norman-Whitaker,

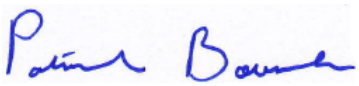
The Ethics Committee of the School of Psychology would like to inform you that at our meeting on the 5.03.2013 your proposal addressing *'the psychological effects of TOPFA and factors that increase or reduce levels of distress following TOPFA?*

Was

☒ **Approved**

It has been allocated the reference number 130305-9b.

Yours sincerely,



Patrick Bourke, PhD
Chair of the Ethics Committee School of Psychology
University of Lincoln
Brayford
Campus
Lincoln
LN6 7TS
United Kingdom
Telephone: +44 (0)1522 886140

Appendix 2 – Advert

Dear ARC members,

Allow me to introduce myself, my name is Zoe Norman-Whitaker and I am a trainee on The Trent Doctorate in Clinical Psychology Programme, a professional training course in clinical psychology. I am carrying out a study exploring the psychological effects of a termination of pregnancy for fetal abnormality.

I am interested in whether the following things affect psychological outcome following a Termination of Pregnancy for fetal abnormality (TOPFA);

- Type of fetal abnormality
- Gestation age at TOPFA
- Method of termination
- Social Support
- Individual Coping style
- perceived agency in decision making

You could help by completing a short online questionnaire and four psychological outcome measures.

You are eligible to participate in our research if you are:

- A UK woman who has bereaved a child due to fetal abnormality.
- Are aged 18 or older
- English speaking/ literate
    - Interviews will be conducted in English.
    - The psychological inventories are all written in English.

Participation in the research is entirely voluntary. You are free to withdraw your participation up to 2 weeks after completing the study. Your responses will be treated confidentially. If you would like to participate in our research, please follow this link _____ and complete the attached questionnaire (taking approximately 20-25 mins).

Don't forget to indicate your consent as you will not be able to proceed without doing so.

If you would like any further information before deciding whether to participate, please contact the Lead Researcher, Zoe Norman-Whitaker, at 05025040@students.lincoln.ac.uk.

Appendix 3 – Details to be placed on the online Survey's Homepage

Trent Doctorate in Clinical Psychology: Thesis

Thank you for your interest in taking part in this study exploring the link between socio-demographic, maternal and obstetric factors and psychological health following a termination of pregnancy for fetal abnormality.

AIMS OF THE STUDY:

The lead researcher is student on The Trent Doctorate in Clinical Psychology Programme, a professional training course in clinical psychology.

I am interested in whether the following things affect psychological outcome following a termination of pregnancy for fetal abnormality (TOPFA);

1. Type of fetal abnormality
2. Gestation age at TOPFA
3. Method of termination
4. Social Support
5. Individual Coping style
6. Perceived agency in decision making

Your participation involves completing a short online questionnaire, three measures of psychological wellbeing and one short questionnaire exploring your coping response. This will help gather details of your personal, medical and obstetric circumstances during your diagnosis and subsequent termination due to fetal abnormality.

PARTICIPATION

You could help by completing a short online questionnaire and four psychological outcome measures.

You are eligible to participate in our research if you are:

- A UK woman who has bereaved a child due to fetal abnormality.
- Are aged 18 or older
- English speaking/ literate
    - Interviews will be conducted in English.
    - The psychological inventories are all written in English.

Potential risks

We understand that some people might find participation difficult, and advise that your participation is entirely voluntary. Should you choose to take part and realise that you are still experiencing distress, you are advised to contact your GP. Additionally, ARC and the following support networks are also available;

http://www.birthtraumaassociation.org.uk/default.asp

http://www.babyloss.com/index.php

http://www.miscarriageassociation.org.uk/

If you would like to participate in our research, please indicate your consent below and complete the questionnaire that follows about your socio-demographic, maternal and obstetric status. It should take approximately 20-25 minutes, depending on your answers. You are free to withdraw your participation up until the date of analysis and your responses will be treated confidentially. You will then be asked to complete 3 brief self report inventories related to mood and psychological distress.

The researcher is making a charitable donation to ARC of £300 to help them continue their good work.

If you would like any further information before deciding whether to participate, please contact the Lead Researcher, Zoe Norman-Whitaker, at 05025040@students.lincoln.ac.uk.

WANT TO HELP?

We would greatly appreciate your participation in our research. If you would like to join this study, please indicate your consent below and complete the following questionnaire.

*****CONSENT*****

CONSENT I have read the participant information above and understand that by clicking the 'Next' button below that I am giving my consent to take part in this survey. I am 18 years or older, and I understand that participation is voluntary and that I am free to stop completing the survey at any time.

Please provide a Pseudo name by combining the first three letters of your mother's maiden name with your month of birth in numerical form _____ (i.e. if your mother's maiden name is Buffrey and you were born in September you should write 'BUF09'.)

Please take note of this name as you will need to quote it if you wish to withdraw your data. You are able to do this up to 2 weeks after submitting your survey.

Please direct any questions to the lead researcher and concerns to University of Lincoln's Ethics board.

The lead researcher Zoe Whitaker may be contacted at:
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United Kingdom
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Appendix 4 - Emails of Support for the study (from participants).

16 August

Dear Zoe,

I posted the link to your study on the boards last night and from my discussions with a number of women who have completed the questionnaire already, it seems to have created a lot of interest – we are all pleased that people are taking the time to research the area! I am not sure at what point you are in your research, but a number of ladies have asked whether they could have a copy of your research once published as they are interested in the results. Would this be possible?

Best Wishes,

Anon

23rd August

Dear Zoe,

I have just completed the survey in relation to your study and I hope that you are getting plenty of responses! Can you tell me how I would go about getting the results from your study once it is complete? I get the impression that a lot of the ladies are quite excited about this research as they really feel not enough is understood about how women cope after TOPFA. I am sure if you ever wanted to take things further and find out what ladies think needs improving/doing to help, plenty of us would be more than willing to give our views.

Thanks,

Anon

Appendix 5- Perinatal Grief Scale

Perinatal Grief Scale

33 Item Short Version

Lori. J. Toedter, Ph.D, Moravian College
And
Judith N Lasker, Ph.D., Lehigh University

Scoring Instructions

The total PGS score is arrived at by first reversing all of the items EXCEPT 11 AND 33. By reversing the items, higher scores now reflect more intense grief. Then add the scores together. The result is a total scale consisting of 33 items with a possible range of 33-165.
The three subscales consist of the sum of the scores of 11 items each, with a possible range of 11-55.

Subscale 1	**Subscale 2**	**Subscale 3**
Active Grief	Difficulty Coping	Despair
1	2	9
3	4	15
5	8	16
6	**11**	17
7	21	18
10	24	20
12	25	22
13	26	23
14	28	29
19	30	31
27	**33**	32

Perinatal Grief Scale

PRESENT THOUGHTS AND FEELINGS ABOUT YOUR LOSS

Each of the items is a statement of thoughts and feelings that some people have concerning a loss such as yours. There are no right or wrong responses to these statements. For each item, tick the box which best indicated the extent to which you agree or disagree with it at the present time. If you are not certain, use the "neither" category. Please try to use this category only when you truly have no opinion.

		Strongly Agree	**Agree**	**Neither Disagree or Agree**	**Disagree**	**Strongly Disagree**
1	I feel depressed					
2	I find it hard to get along with people					
3	I feel empty inside					
4	I can't keep up with my normal activities					
5	I feel a need to talk about the baby					
6	I am grieving for the baby					
7	I am frightened					
8	I have considered suicide since the loss					
9	I take medicine for my nerves					
10	I very much miss the baby					
11	I feel I have adjusted well to the loss					
12	It is painful to recall memories of the loss					
13	I get upset when I think about the baby					
14	I cry when I think about him/her					

15	I feel guilty when I think about the baby					
16	I feel physically ill when I think about the baby					
17	I feel unprotected in a dangerous world since					
18	I try to laugh, but nothing seems funny anymore					
19	Time passes so slowly since the baby died					
20	The best part of me died with the baby					
21	I have let people down since the baby died					
22	I feel worthless since he/she died					
23	I blame myself for the baby's death					
24	I get cross at my friends and relatives					
25	Sometimes I feel like I need a professional counsellor to help me					
26	I feel as though I'm just existing and not really living					
27	I feel so lonely since he/she died					
28	I feel somewhat apart and remote, even among friends					
29	It's safer not to love					
30	I find it difficult to make decisions since the baby					
31	I worry about what my future will be like					
32	Being a bereaved parent means being a "Second-					
33	It feels great to be alive					

Appendix 6 - Brief Cope

Brief COPE

These items deal with ways you've been coping with the stress in your life since your termination. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how **you've** tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.

26. I’ve been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation

Self-distraction, items 1 and 19
Active coping, items 2 and 7
Denial, items 3 and 8
Substance use, items 4 and 11
Use of emotional support, items 5 and 15
Use of instrumental support, items 10 and 23
Behavioural disengagement, items 6 and 16
Venting, items 9 and 21
Positive reframing, items 12 and 17
Planning, items 14 and 25
Humour, items 18 and 28
Acceptance, items 20 and 24
Religion, items 22 and 27
Self-blame, items 13 and 26

Appendix 7

IMPACT OF EVENT SCALE-REVISED

Instructions: The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you with respect to the TOPFA. How much were you distressed or bothered by these difficulties?

		Not at all	A little bit	Moderate-ly	Quite a bit	Ex-treme-ly
1	Any reminder brought back feelings about it.	0	1	2	3	4
2	I had trouble staying asleep.	0	1	2	3	4
3	Other things kept making me think about it.	0	1	2	3	4
4	I felt irritable and angry.	0	1	2	3	4
5	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	2	3	4
6	I thought about it when I didn't mean to.	0	1	2	3	4
7	I felt as if it hadn't happened or wasn't real.	0	1	2	3	4
8	I stayed away from reminders about it.	0	1	2	3	4
9	Pictures about it popped into my mind.	0	1	2	3	4
10	I was jumpy and easily startled.	0	1	2	3	4
11	I tried not to think about it.	0	1	2	3	4
12	I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3	4
13	My feelings about it were kind of numb.	0	1	2	3	4
14	I found myself acting or feeling like I was back at that time.	0	1	2	3	4
15	I had trouble falling asleep.	0	1	2	3	4
16	I had waves of strong feelings about it.	0	1	2	3	4
17	I tried to remove it from my memory.	0	1	2	3	4
18	I had trouble concentrating.	0	1	2	3	4
19	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
20	I had dreams about it.	0	1	2	3	4
21	I felt watchful and on guard.	0	1	2	3	4
22	I tried not to talk about it.	0	1	2	3	4

Appendix 8 – HADS

Hospital Anxiety and Depression Scale (HADS)

Patients are asked to choose one response from the four given for each interview. They should give an immediate response and be dissuaded from thinking too long about their answers. The questions relating to anxiety are marked "A", and to depression "D". The score for each answer is given in the right column. Instruct the patient to answer how it currently describes their feelings.

A	**I feel tense or 'wound up':**	
	Most of the time	3
	A lot of the time	2
	From time to time, occasionally	1
	Not at all	0
D	**I still enjoy the things I used to enjoy:**	
	Definitely as much	0
	Not quite so much	1
	Only a little	2
	Hardly at all	3
A	**I get a sort of frightened feeling as if something awful is about to happen:**	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0
D	**I can laugh and see the funny side of things:**	
	As much as I always could	0

	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3
A	**Worrying thoughts go through my mind:**	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not too often	1
	Only occasionally	0
D	**I feel cheerful:**	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0
A	**I can sit at ease and feel relaxed:**	
	Definitely	0
	Usually	1
	Not Often	2
	Not at all	3
D	**I feel as if I am slowed down:**	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0

A	**I get a sort of frightened feeling like 'butterflies' in the stomach:**	
	Not at all	0
	Occasionally	1
	Quite Often	2
	Very Often	3
D	**I have lost interest in my appearance:**	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care as ever	0
A	**I feel restless as I have to be on the move:**	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0
D	**I look forward with enjoyment to things:**	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3
A	**I get sudden feelings of panic:**	
	Very often indeed	3
	Quite often	2

	Not very often	1
	Not at all	0
D	**I can enjoy a good book or radio or TV program:**	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

	Scoring (add the As = Anxiety. Add the Ds = Depression). The norms below will give you an idea of the level of Anxiety and Depression.	
	0-7 = Normal	
	8-10 = Borderline abnormal	
	11-21 = Abnormal	

Appendix 9 Table 11 Summary of Hierarchical Regression Analysis for factors predicting Depression as measured by the HADS-D *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*B*	*B*	SE	*β*	*B*	SE	*β*
Congenital Abnormality	0.35	1.82	.03	.49	1.60	.04	.25	1.49	.02
Chromosomal Anomaly	-0.83	1.65	-.09	-1.22	1.46	-.13	-.88	1.43	-.09
Nervous System Anomaly	-1.76	1.79	-.17	-1.05	1.58	-.10	-1.72	1.50	-.16
Medical Termination	0.32	1.04	.03	-1.41	.96	-.15	-.41	.90	-.04
Surgical Termination	1.11	1.61	.08	-.30	1.44	-.02	-1.63	1.38	-.11
Decision to terminate	-0.42	0.55	-.08	-.49	.50	-.09	-.67	.46	-.12
Decision in method	-0.46	0.32	-.14	-.52	.28	-.16	-.31	.26	-.09
Social support				-.80	.26	-.29**	-.32	.24	-.12
Time since termination				-1.51	.27	-.54****	-.96	.26	-.34****
Coping through Religion							-.05	.23	-.02
Self-Distraction							.07	.24	.03
Active Coping							-.28	.30	-.10
Denial							-.04	.41	-.01
Substance use							.38	.28	.11
Use of emotional support							-.51	.26	-.20
Use of instrumental support							.17	.26	.07

Behavioural Disengagement			1.39	.37	.34****
Venting			.07	.27	.02
Positive Reframing			-.04	.23	-.02
Planning			.54	.27	.22*
Humour			-.08	.34	-.02
Acceptance			-.50	.33	-.16
Self- blame			.52	.21	.21**
R^2	**0.049**	**0.280**		**0.560**	
***F* for change in R^2**	**0.774**	**4.496*** **		**4.973*** **	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Appendix 10 Table 12 Summary of Hierarchical Regression Analysis for factors predicting Anxiety as measured by the HADS-A *(N=122)*

Variable	Model 1			Model 2			Model 3		
	B	SE	*β*	*B*	SE	*β*	*B*	SE	*β*
Congenital Abnormality	0.62	1.95		.80	1.79	.06	.94	1.68	.07
Chromosomal Anomaly	-0.20	1.76		-.43	1.64	-.04	.02	1.61	.00
Nervous System Anomaly	-0.60	1.91		.10	1.77	.01	-.11	1.69	-.01
Medical Termination	1.22	1.11		-.33	1.07	-.03	.46	1.01	.04
Surgical Termination	2.28	1.71		1.13	1.61	.07	-.38	1.56	-.02
Decision to terminate	0.79	0.59		.66	.56	.11	.43	.52	.07
Decision in method	-0.61	0.35		-.67	.32	-.19*	-.47	.30	-.13
Social support				-.58	.29	-.20*	-.19	.27	-.07
Time Since Termination				-1.37	.30	-.45****	-.83	.29	-.28**
Coping through Religion							-.04	.26	-.01
Self-Distraction							.20	.27	.07
Active Coping							-.07	.34	-.02
Denial							.00	.46	.00
Substance use							-.05	.31	-.01
Use of emotional support							-.59	.30	-.22
Use of instrumental support							.16	.29	.06

Behavioural Disengagement			1.06	.42	.24*
Venting			.62	.30	.20*
Positive Reframing			.08	.26	.03
Planning			.56	.31	.21
Humour			.05	.38	.01
Acceptance			-.66	.37	-.20
Self- blame			.56	.23	.21*
R^2	**0.068**	**0.227**		**0.518**	
F **for change in** R^2	**1.109**	**3.390**		**4.210**	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Appendix 11Table 13 Summary of Hierarchical Regression Analysis for factors predicting Grief as measured by the PGS-33 *(N=122)*

	Model 1			Model 2			Model 3		
Variable	*B*	SE	*β*	*B*	SE	*β*	*B*	SE	*β*
Congenital Abnormality	1.28	9.04	.02	1.82	7.83	.03	4.91	6.45	.08
Chromosomal Anomaly	-2.54	8.19	-.06	-5.03	7.15	-.11	-.13	6.19	.00
Nervous System Anomaly	-4.52	8.88	-.09	-1.15	7.73	-.02	-3.35	6.49	-.06
Medical Termination	0.27	5.14	.01	-8.57	4.68	-.18	-7.37	3.89	-.16
Surgical Termination	9.39	7.96	.13	1.64	7.05	.02	-11.49	6.00	-.16
Decision to terminate	1.33	2.72	.05	1.27	2.43	.05	1.26	2.01	.05
Decision in method	-2.62	1.61	-.16	-2.98	1.39	-.18*	-.89	1.14	-.06
Social support				-4.68	1.26	-.34****	-2.32	1.05	-.17*
Time Since Termination				-7.62	1.31	-.55****	-4.87	1.12	-.35****
Coping through Religion							.52	.99	.04
Self-Distraction							.77	1.05	.06
Active Coping							-1.41	1.29	-.10
Denial							-1.04	1.76	-.05
Substance use							.30	1.20	.02
Use of emotional support							-.09	1.15	-.01
Use of instrumental support							-.73	1.12	-.06

Behavioural Disengagement			3.73	1.60	.18*
Venting			2.05	1.15	.15
Positive Reframing			-1.08	1.00	-.09
Planning			2.33	1.19	.19
Humour			-1.15	1.47	-.06
Acceptance			-3.82	1.42	-.25**
Self- blame			5.01	.89	.42****
R^2	**0.042**	**0.297**		**0.661**	
***F* for change in R^2**	**0.662**	**4.874**		**7.663**	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Appendix 12 Table 17 Summary of Hierarchical Regression Analysis for factors predicting symptoms of post-traumatic stress as measured by the IES

Variable	Model 1			Model 2			Model 3		
	B	SE	*B*	*B*	SE	*β*	*B*	SE	*β*
Congenital Abnormality	0.21	6.95	.00	.80	6.27	.02	1.17	5.64	.03
Chromosomal Anomaly	-0.76	6.29	-.02	-1.92	5.72	-.05	.19	5.41	.01
Nervous System Anomaly	-6.16	6.82	-.16	-3.56	6.18	-.09	-6.16	5.67	-.16
Medical Termination	-0.50	3.95	-.01	-6.55	3.75	-.18	-4.64	3.40	-.13
Surgical Termination	0.63	6.12	.01	-4.10	5.64	-.07	-12.42	5.25	-.22*
Decision to terminate	0.91	2.09	.04	.53	1.94	.03	-.12	1.76	-.01
Decision in method	-0.98	1.23	-.08	-1.22	1.11	-.10	-.08	1.00	-.01
Social support				-2.55	1.01	-.25*	-1.07	.92	-.10
Time Since Termination				-5.32	1.05	-.50****	-3.04	.98	-.29**
Coping through Religion							.24	.87	.02
Self-Distraction							.40	.92	.04
Active Coping							-.93	1.13	-.09
Denial							2.45	1.54	.14
Substance use							2.30	1.05	.17*
Use of emotional support							-.77	1.00	-.08
Use of instrumental support							.08	.98	.01

Behavioural Disengagement			3.31	1.40	.21*
Venting			-.71	1.01	-.07
Positive Reframing			.47	.87	.05
Planning			2.47	1.04	.27*
Humour			-1.55	1.29	-.10
Acceptance			-2.08	1.24	-.18
Self- blame			2.96	.78	.32****
R^2	**0.030**	**0.228**		**0.556**	
***F* for change in R^2**	**0.467**	**3.413**		**4.903**	

* p <0.05 **p < 0.01 ***p < 0.001 **** p < 0.0001

Appendix 13 Online survey schedule

ABOUT YOU….

1. **Age**

18-19	☐
20 -24	☐
25-29	☐
30-34	☐
35 – 39	☐
40 – 4 4	☐
45+	☐

2. **Time since termination Please indicate from drop down**

3. **Relationship status: Please indicate**

Married	Now	At time of termination
Cohabiting	☐	☐
Divorced/ Separated	☐	☐
Civil partnership	☐	☐
Widowed	☐	☐
Single	☐	☐

4. **Which of the following categories best describes your employment status?**

	Now	At time of termination
Employed, full time	☐	☐
Employed, part time	☐	☐
Not employed, looking for work	☐	☐
Not employed, NOT looking for work	☐	☐
Retired	☐	☐
Disabled, not able to work	☐	☐

5. **Can you tell me the highest educational or school qualification you have obtained? Please indicate**

University Higher Degree (e.g. MSc, PhD)	Pass ☐ Merit ☐ Distinction ☐
First degree level qualification including foundation degrees, graduate (e.g. BSc, BA)	1st☐ 2:1☐ 2:2☐ 3rd ☐ pass☐
membership of a professional Institute, PGCE	☐
Diploma in higher education	Distinction ☐ Merit ☐
Teaching qualification (excluding PGCE)	☐
Nursing or other medical qualification not yet mentioned	☐
A Level	A*grade ☐ A grade ☐ B grade ☐ C grade ☐ D grade ☐ E grade ☐
Welsh Baccalaureate	Foundation Diploma ☐ Intermediate Diploma ☐ Advanced Diploma ☐
International Baccalaureate	☐
AS Level	A*grade ☐ A grade ☐ B grade ☐ C grade ☐ D grade ☐ E grade ☐
Higher Grade/Advanced Higher (Scotland)	☐
Certificate of sixth year studies	☐
GCSE/O Level	A*grade ☐ A grade ☐ B grade ☐ C grade ☐ D grade ☐ E grade ☐ F grade ☐ G grade ☐
CSE	☐
Standard/Ordinary (O) Grade / Lower (Scotland)	☐
Other school (inc. school leaving exam certificate or matriculation)	☐
None of the above	☐
Other (Please Specify)	

6. **Ethnicity: Please indicate**

White	
British	☐
Irish	☐
Any other White background	☐
Mixed	
White and Black Caribbean	☐
White and Black African	☐
White and Asian	☐
Any other mixed background	☐
Asian or Asian British	
Indian	☐
Pakistani	☐
Bangladeshi	☐
Any other Asian background	☐
Black or Black British	
Caribbean	☐
African	☐
Any other Black background	☐
Other Ethnic Groups	
Chinese	☐
Any other ethnic group	☐
Prefer not to state	☐

7. **Religious/ belief system affiliation: Please indicate**

	Practicing	Non-Practicing
Baha'i	☐	☐
Buddhist	☐	☐
Christian	☐	☐
Hindu	☐	☐
Jain	☐	☐
Jewish	☐	☐
Muslim	☐	☐
Pagan	☐	☐
Sikh	☐	☐
Zoroastrian	☐	☐
Other _____	☐	☐
None	☐	
Decline to Disclose	☐	

About your pregnancies….

8. Tell us about the number of times you have been pregnant and how many children you currently have

Number of pregnancies		**Current number of children**	
1 pregnancy	☐	No children	☐
2 pregnancies	☐	1 child	☐
3 pregnancies	☐	2 children	☐
4 pregnancies	☐	3 children	☐
5 pregnancies	☐	4 children	☐
More than 5 pregnancies	☐	5 children	☐
		More than 5 children	☐

You will now be asked a number of questions specifically about the pregnancy that was terminated due to foetal abnormality. It is possible that you may have had multiple terminations for foetal abnormality, if so please answer the following questions with the most recently affected pregnancy in mind.

9. Was the terminated pregnancy a multiple pregnancy?

Yes ☐ No ☐

Please proceed to question 11 Please proceed to question 12

10. Multiple Pregnancies

I was expecting	The number of affected foetuses were;
Twins	1 ☐ Both ☐
Triplets	1 ☐ 2 ☐ All ☐
Quadruplets	1 ☐ 2 ☐ 3 ☐ All ☐

11. Which foetal abnormality was diagnosed? Please indicate

Chromosome anomaly	☐
Trisomy 13	☐
Trisomy 18	☐
Trisomy 21	☐
Triploidy	☐
Turners syndrome	☐
Neural Tube Defect	☐
Spina Bifida	☐
Anencephaly	☐
Encephalocele	☐
Meckel Gruber	☐
Neuromuscular Disorder	☐
Hemophilia	☐
Uropathy	☐
Isolated cardiac anomaly	☐
Skeletal dysplasia	☐
Other isolated anomaly (hydrocephaly, omphalocéle)	☐
Metabolic anomaly	☐
Multiple malformation	☐
Other_____	☐
Unknown	☐

12. Please indicate at which week in your pregnancy the following occurred;

a) Diagnosis Week number (please indicate)
b) Termination Week number (please indicate)

13. **Please indicate the method of termination that was used**

Medical (medical terminations do not involve surgery but involve taking the drug mifepristone)	☐
Surgical	
Dilation and Aspiration (D&A)	☐
Dilation and Curettage (D&C)	☐
Dilation and Evacuation (D&E)	☐
Induction of labour	☐
Method unknown	☐

14. When we are required to make decisions about the treatment that we receive, we each have different ideas about how involved we want to be in the decision making process. Please indicate from the following options, how you prefer to reach treatment decisions (in general).

When I have general treatment decisions to make:	
I prefer to make the final selection about which treatment I will receive.	☐
I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.	☐
I prefer that my doctor and I share responsibility for deciding which treatment is best for me.	☐
I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.	☐
I prefer to leave all decisions regarding my treatment to my doctor.	☐

15. You have indicated your ideal level of involvement when making general treatment decisions. Now please indicate your perceived level of involvement in the decision to terminate the pregnancy.

In choosing to terminate the pregnancy:	
I made the final decision to terminate	☐
I made the final decision to terminate after seriously considering my doctor's opinion.	☐
My doctor and I shared responsibility for deciding on termination.	☐
My doctor made the final decision about termination but seriously considered my opinion.	☐
My doctor made all the decisions regarding my termination	☐

16. Now indicate your perceived level of involvement in deciding which method of termination would be used.

Method of termination	
I made the final selection about the method of termination	☐
I made the final selection about method of termination after seriously considering my doctor's opinion.	☐
My doctor and I shared responsibility for deciding which method of termination was best for me.	☐
My doctor made the final decision about which method of termination would be used but seriously considered my opinion.	☐
My doctor made all the decisions regarding method of termination.	☐

17. Please indicate the type of social support that you received and how satisfied you were with the level of support

I am (was) satisfied that I can (could) turn to this person for help during my pregnancy and when I received the diagnosis of foetal abnormality.			
	Hardly Ever	**Some of the time**	**Almost always**
The Father	☐	☐	☐
My Mother	☐	☐	☐
My Father	☐	☐	☐
Other Family	☐	☐	☐
My Friends	☐	☐	☐
Health Professionals	☐	☐	☐
Other People I know	☐	☐	☐
I am (was) satisfied with the way this person talks(ed) things over with me and/ or shares(ed) the decision to terminate the pregnancy.			
	Hardly Ever	**Some of the time**	**Almost always**
The Father	☐	☐	☐
My Mother	☐	☐	☐

My Father	☐	☐	☐
Other Family	☐	☐	☐
My Friends	☐	☐	☐
Health Professionals	☐	☐	☐
Other People I know	☐	☐	☐
I am (was) satisfied that this person accepts(ed) and supports(ed) me to take on new activities or make changes in my lifestyle			
	Hardly Ever	**Some of the time**	**Almost always**
The Father	☐	☐	☐
My Mother	☐	☐	☐
My Father	☐	☐	☐
Other Family	☐	☐	☐
My Friends	☐	☐	☐
Health Professionals	☐	☐	☐
Other People I know	☐	☐	☐
I am satisfied with the way this person expressed and responded to my emotions such as anger, sorrow, or love during my pregnancy, diagnosis and since termination.			
	Hardly Ever	**Some of the time**	**Almost always**
The Father	☐	☐	☐
My Mother	☐	☐	☐
My Father	☐	☐	☐
Other Family	☐	☐	☐
My Friends	☐	☐	☐
Health Professionals	☐	☐	☐
Other People I know	☐	☐	☐

I am (was) satisfied with the way this person and I share(ed) time together during my pregnancy, diagnosis and since termination			
	Hardly Ever	**Some of the time**	**Almost always**
The Father	☐	☐	☐
My Mother	☐	☐	☐
My Father	☐	☐	☐
Other Family	☐	☐	☐
My Friends	☐	☐	☐
Health Professionals	☐	☐	☐
Other People I know	☐	☐	☐

I would like to hear in your words about your experience of terminating a pregnancy for foetal abnormality. Please use the headings below to describe your reaction.

18. In the first week after the termination I remember having the following;

Thoughts
Feelings
Behaviours

19. Please tell us about the things that helped you at the time to deal with your distress.

20. Finally, please tell us how you currently think, feel and behave in response to your experience of terminating a pregnancy for foetal abnormality.

Thoughts
Feelings
Behaviours

17.0 References

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